

An Examination of the Usability of Online Consumer Health Information by Information Professionals

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INTRODUCTION

With the advent of the Internet in the last decade, people increasingly forego traditional methods of health information gathering, and focus more and more on the World Wide Web (Cline and Hayes). By the sheer number of health information websites, which Wilson estimates to be over 100,000, we can assume that more information is being made available to more individuals. Indeed, many people believe the Internet is the ideal way to not only find information, but to take control of one's own health care (Huber et al., Crandall et al., Thompson, Hern et al.). The Internet, then, is allowing more people to take charge of their own health and access health information as never before.

Nevertheless, there are still people who do not have Internet access ("Canadian Internet Use Study"). As well, there are those who have Internet access, but are not proficient enough in searching the Internet to find relevant and valid health information. Where do these individuals go for health information? In our current environment, doctors and nurses are too busy to go over all the health information related to a condition with a patient, and other health care professionals may not be up-to-date in the literature regarding any particular ailment. Information professionals are one group to whom an individual will turn when they want to find certain health information but cannot do so themselves (Press and Diggs-Hobson). Information professionals can assist their patrons in finding relevant, valid, reliable, and quality health information related to their particular question.

There have been several studies conducted over the years discussing the reliability and validity of consumer health information websites (Impicciatore et al., Sandvik, Diaz et al., Dutta-Bergman, Craan and Oleske), examining how the lay person works their way through the Internet to find health information (Spink et al., Morahan-Martin), considering

the quality of consumer health information websites (Scott, Scott and Auld), and viewing the consumer health librarian as health advocate (Spatz). Indeed, there is no lack of research on this topic. However, there is a dearth of studies which focus on how information professionals navigate through the numerous consumer health information websites. How do information professionals search the Internet to find the health information they are looking for? If a patron presents them with a reference question, will they be able to manoeuvre through the myriad of possible websites to provide quality information? In general, studies looking at the information-seeking behaviour of information professionals are few and far between; the investigators could only find a few articles that specifically examined information professionals' information-seeking behaviour (Tabatabai and Shore; Brown and Ortega; Garnes and Mills). Tabatabai and Shore framed their question as how experts and novices search the web; it so happened that their experts included seasoned librarians and their novices included Library and Information Science students near the end of their Masters degree. Masters students in Library and Information Science programs are often used as subjects in experiments, but likely the examiners focus more on what "searchers" do, and do not frame their question to what professionals in the information field do (McKenzie). This study, then, is opening new ground for this area of examination.

This study aims to fill this gap in the research, focusing on how information professionals search for health information on the Internet. Specifically, this project set out to answer the following questions:

- What pathways do information professionals take when using the Internet to find an answer to a health query?
- How long does it take for an information professional to find a "best" answer (in both time and number of webpages visited)?
- Are information professionals able to find a "best" answer to a consumer health question?
- Does exposure to training in consumer health information affect whether or not an information professional finds a "best" answer?

This study extends a previous study that assessed the usability, accessibility, and redundancy of a set of health information websites, portals, and search engines in finding

answers to specific health queries (Fear, Harris, and Wathen). In the current study, the investigators are examining the proficiency of information professionals in using the same set of health information websites, portals, and search engines to find an answer to the same set of health queries.

The health queries used in both the previous study and the current study are the following:

- How can I control my menopausal hot flashes?
- How can I tell if I have osteoporosis? What, specifically, can I do to prevent it?
- My husband has just been diagnosed with prostate cancer. What will he be going through, and what can I expect to happen?
- My child has had several painful ear infections and I'm worried whether she might suffer permanent hearing loss. I've seen other children with tubes in their ears. Should my child have these tubes?
- My mother is increasingly forgetful and I'm worried that she may have Alzheimer Disease. How do I know if she has Alzheimer's and what should I do?

These questions represent common questions about common health diseases, conditions, and ailments. They represent a range of ailments, including conditions that occur only to a certain gender or age group. Any information professional in a public library setting could expect to be asked such questions.

Eighteen different websites, portals, and search engines were utilized. Below the resources are listed, along with a short description of each:

Websites

- **HealthyOntario.com** (<http://www.healthyontario.com>) – This site is owned by the Ontario Government and operated by the Ontario Ministry of Health Promotion, independently of corporate and private companies. The content for this website is provided by “leading healthcare and medical experts, and from partnerships with not-for-profit organizations focused on health and wellness” (http://www.healthyontario.com/About_Us.htm).
- **Health Canada – It's Your Health** (http://www.hc-sc.gc.ca/iyh-vsv/index_e.html) – This site contains a series of articles, written in consultation with Health Canada and the Public Health Agency's scientists and experts, which covers a wide range of health issues (http://www.hc-sc.gc.ca/iyh-vsv/about-apropos_e.html).
- **Sympatico Health MediResource** (<http://mediresource.sympatico.ca/index.asp>) – The content of this site is populated by MediResource, a consumer health database that includes drug, disease, and patient self-management information and tools.
- **MedBroadcast** (<http://www.medbroadcast.com>) – The content of this site is also populated by MediResource.

- **Mayo Clinic CHI Site** (<http://www.mayoclinic.com>) – This site provides information from the “world’s first and largest integrated, not-for-profit group medical practice” and contains information that “reflect the expertise of Mayo’s 2,500 physicians and scientists” (<http://www.mayoclinic.com/health/medical/AboutMayoClinic>).
- **UK National Health Service’s NHS Direct Online** (<http://www.nhsdirect.nhs.uk>) – This site provides “fast and convenient public access to information, advice and care through online information services [from the National Health Service]” (<http://www.nhs.uk/England/AboutTheNhs/History/1998ToPresent.cmsx>).
- **MedlinePlus (US National Library of Medicine)** (<http://www.nlm.nih.gov/medlineplus>) – This site directs users to authoritative information from National Library of Medicine, the National Institutes of Health, and other government agencies and health-related organizations to help answer health-related questions (<http://www.nlm.nih.gov/medlineplus/aboutmedlineplus.html>).

Portals

- **Canada Health Portal** (<http://www.chp-pcs.gc.ca/index.jsp>) – This portal “provides Canadians with an authoritative and integrated view of health information and services from various government jurisdictions and organizations across Canada” (http://chp-pcs.gc.ca/CHP/index_e.jsp?pageid=10086).
- **Canadian Health Network** (<http://www.canadian-health-network.ca/>) – This is a bilingual health information service that provides information from Public Health Agency Canada and Health Canada, as well as from national and provincial non-profit organizations, hospitals, libraries, and so forth.
- **Nova Scotia Health Network** (<http://www.nshealthnetwork.org>) – Provides both local and global information on health. Provides links to both profit and not-for-profit organizations.
- **Alberta Health & Wellness Healthier Living** (<http://www.health.gov.ab.ca>) – From the Government of Alberta, this portal provides information for both the consumer and for health professionals.
- **Yahoo Canada Health** (<http://ca.dir.yahoo.com/Regional/Countries/Canada/Health>) – This portal provides links to health information websites, both Canadian and global, from both not-for-profit and profit organizations.
- **Google Health** (<http://directory.google.com/Top/Health>) – This portal provides links to health information websites, both Canadian and global, from both not-for-profit and profit organizations.
- **US National Institutes of Health** (<http://health.nih.gov>) – This portal is supported by the National Institutes of Health, Department of Health and Human Services, and FirstGov. This portal provides access to health information on various conditions from many different websites. Some information provided in Spanish.

Search Engines

- **Google** (<http://www.google.ca>) – A popular general search engine. It allows users to limit search to information from Canada.

- **Yahoo** (<http://www.yahoo.com>) – A popular general search engine. This site also provides news, entertainment options, and various services.
- **MSN** (<http://www.msn.com>) – A popular general search engine. This site also provides news, entertainment options, and various services.
- **Ask** (<http://search.ask.com/>) – A general search engine.

As with the health queries, these resources were used because they are popular or common resources. Some resources were selected because they are examples of services promoted by governments as a response to citizens' health information needs (such as Health Canada-IYH, HealthyOntario.com and the United Kingdom's National Health Service Online). Others were selected because they are widely regarded as important and credible sources of health information (e.g. MedlinePlus and the Mayo Clinic). Commercial websites (such as Sympatico Health and MedBroadcast) were also included to enable comparisons of their content with that found on or through government sites. General search engines were used because individuals may not be aware of a specific resource, and would instead search for health information using a search engine. The resources also represent both Canadian and International information.

METHODOLOGY

To answer the questions posed, the investigators invited students enrolled in their second or third term of the Master of Library and Information Science program at The University of Western Ontario (UWO) to take part in the study. It is assumed that these students will closely approximate the information-seeking behaviours of information professionals because of their exposure to Library and Information Science theories and practices.

The investigators specifically recruited students who were enrolled in the Consumer Health Information course (LIS 584). Because it is possible that students enrolled in LIS 584 were self-selected, a comparison group of students enrolled in non-health information courses and who have not taken LIS 584 in the past were also recruited. Those currently enrolled in LIS 584 were asked to participate in the study twice, once at the very beginning

of the LIS 584 course (after the first class but before the second class) and once near the end of the course (after the tenth class), so that the investigators could gauge any differences in searching after students had had a good deal of exposure to consumer health information resources. Students who were not in LIS 584 (hereinafter referred to as "Others") only took part once, within the first few weeks of the term.

Two computer software programs were utilized for this project to record the participant's sessions:

- Camtasia – A motion screen capture software that records, in real-time, the various sites and pages visited.
- SQUID – A Web proxy cache system that stores all URLs visited during a session.

Some problems arose in using the software, which will be discussed below.

Participants were randomly assigned one of the consumer health queries, with those enrolled in LIS 584 receiving a different question during their second session than their first. This was accomplished by the investigators keeping track of what question each LIS 584 participant received during their first session, and taking that question out of the process when randomly assigning the second question. Participants using SQUID were also given a random sample of websites, portals, and search engines to use; they had to find what they considered the best answer to the question using three resources, one from each category. Those using Camtasia were not provided any resources, and were asked to search for an answer to the query using any resource they choose. Allowing some participants to choose their own resources enabled the researchers to examine what resources are used when the participant is not given any direction. All participants were given a maximum time of 20 minutes to find what they consider to be the "best" answer to the question. This time limit was set in order to simulate a real-world reference situation. Participants using Camtasia were asked to stop searching when they believed they had found the best answer to the query. Participants using SQUID were asked to search for the best answer in all three resources provided, halting their search in each resource when they thought they had found the best answer.

After the first round of participants was completed and the data analysed, the investigators realized that the SQUID program did not provide them with the data they expected. Upon careful reflection and discussion, it was decided that the SQUID data could not be used and were discarded. As more participants had used SQUID than Camtasia, several more Other participants had to be recruited to use Camtasia. Those participants were provided a randomly assigned health query, and were given a random sample of websites, portals, and search engines to use. The instructions for these participants were the same as for participants who used SQUID (see above). These participants were given resources in which to search because, with the SQUID data unusable, the investigators had no sessions where participants searched using assigned resources.

Because of the problems using SQUID, Camtasia was used to record the searching of all the participants who took part in the second round of testing. All 13 participants from the LIS 584 class who agreed to take part in the first session also agreed to participate in the second session. Participants were randomly assigned either no resources or were given a random sample of websites, portals, and search engines to use, with the instructions the same as outlined above.

The Camtasia data was analysed by viewing the resulting videos. The pathways the participants took to find what they considered the best answers to the queries, the length of time taken, the number of webpages visited, and how the information professionals defined a best answer were assessed. If the participants were not given any specific resources to use, the investigators compared their ultimate answers to answers provided by the Merck Manual Home Edition.¹ The Merck Manual was used because it is acknowledged as providing detailed and effective health information. If the participants were given specific resources to search, their answers were compared to answers the investigators could find in the same resources. For each website, portal, and search engine, the investigators conducted a basic search and examined the first three non-sponsored hits that were presented in each. This

¹ <http://www.merck.com/mmhe/index.htm>.

strategy was employed because, while the resources themselves may not have “Merck-quality” answers, some kind of controlled comparison must be made. The investigators limited their search to the first three non-sponsored hits because it is assumed that an answer should be found in the first three results; users will not want to dig down through too many resources to find an answer to their question (Nicholas et al.). The investigators also limited their search to the top three sites in order to keep the search manageable; a person could literally search for hours for information, and the investigators needed some mechanism to limit the amount of time spent and information found. Since the Merck and investigator answers will be referred to repeatedly throughout this paper, the answers are attached as appendices.

FIRST ROUND OF TESTING

Thirteen LIS 584 participants agreed to take part in the first round. Ten participants' searches were captured using SQUID, while three participants' search was captured using Camtasia. As mentioned above, SQUID data turned out to be inadequate; therefore, only three sessions from participants from LIS 584 could be used for analysis. The investigators could not recruit more LIS 584 participants because, given the time delay, they would have had more exposure to consumer health information resources and that may have affected on the results.

When recruiting Other participants, the investigators wanted to have the same number of non-LIS 584 participants as LIS 584 participants; therefore, 13 Other participants were recruited. As with the LIS 584 participants, ten participants used SQUID and three participants used Camtasia. Once the investigators found out the SQUID data was inadequate, more participants were recruited in order to increase the amount of data. Four more Other participants agreed to participate; each of these participants completed their searches using Camtasia. The investigators randomly assigned each of the four Other participant one resource from each of the categories of health information resources.

In total, the investigators analysed data from ten participants from the first round of testing. Below, pertinent information from each participant's search is provided.

Other A

Question: Osteoporosis
Session time: 10:49
Resources provided?: No
Websites visited: 5
Pages visited: 24

The participant began their search using a specific resource. He or she went directly to Wikipedia.² In reference to the Merck answer, attached as Appendix 2, Wikipedia provided the least amount of information. Wikipedia provides information on calcium, and there is mention of people needing 1,500 mg of calcium per day. Wikipedia also discussed how calcium should be taken (dairy products and supplements), and mentioned that dairy products may not be the best calcium source. Vitamin D was barely discussed, with no recommendation of the amount of vitamin D that should be taken per day. There was also no discussion of exercise or medications. Wikipedia did discuss signs of osteoporosis, but provided more information on risk factors.

The person then looked at a page from The National Osteoporosis Foundation (NOF). The NOF provided much better information about the prevention of osteoporosis than Wikipedia.³ The NOF outlined the reasons why calcium and vitamin D are needed, and listed the amount of each that people should ingest each day—although the amount of calcium listed differed from the amount of calcium indicated in the Merck manual. The NOF also discussed exercises, available medications, and bone density tests. Also outlined were five steps to bone health and osteoporosis prevention:

- Get your daily recommended amounts of calcium and vitamin D
- Engage in regular weight-bearing exercise
- Avoid smoking and excessive alcohol
- Talk to your healthcare provider about bone health
- Have a bone density test and take medication when appropriate.

² <http://en.wikipedia.org/wiki/Osteoporosis>.

³ <http://www.nof.org/prevention/index.htm>.

The participant also found some information regarding symptoms of osteoporosis from the NOF website, but it was not in great detail. The person found a webpage in NOF giving basic facts on osteoporosis.⁴ This page, which is very long, devotes only nine lines to symptoms. The NOF does not provide the detailed symptoms information that Merck does.

The last place the person found an answer was AllRefer.com, which provided very basic information. The site mentions that, at the onset, there are often no symptoms.⁵ AllRefer.com then listed symptoms that occur later with the disease, including fractures, low back pain, neck pain, bone pain or tenderness, loss of height over time, and stooped posture. The Merck manual mentions most of these issues, but discusses them in more detail. However, AllRefer.com made four of the six symptoms "clickable," so that if the user wants to find out more about a particular symptom, they just have to click on the link. This participant did not open any of the links; therefore, the information from AllRefer.com (as the participant found it) is incomplete. The participant did not open the link for information on prevention; he or she looked at a page about treatment, but not prevention. Therefore, a full answer the question was not found using this resource.

With each website visited, the participant started off doing a search for osteoporosis, and then dug down through the resulting links to find an answer. At times the osteoporosis search was qualified by including the search term "diagnosis." The participant began by immediately going to Wikipedia, meaning that a particular resource was in mind when the search began. Afterward, the participant went to Google.com and completed a search. After what the investigators consider to be the final time the participant answered the question, this person continued to search for information. In fact, the last answer found occurred at approximately 6:30; the participant continued searching for extra information for another 4:19. During this extra search, the person looked at the following information: what is osteoporosis; fast facts; frequently asked questions; find a doctor; BBQ and car wash at

⁴ <http://www.nof.org/prevention/index.htm>.

⁵ <http://health.allrefer.com/health/osteoporosis-symptoms.html>.

Osteoporosis Canada in London, Ontario; and events happening in London, Ontario. Although each participant was informed to stop searching once an answer was found, this person continued to search.

Other B

Question: Osteoporosis
Session time: 10:46
Resources provided?: No
Websites visited: 6
Pages visited: 33

This person found what could be considered answers at several different points during the session. However, from the movement of the mouse and the fact that this person's session ended after two links in one webpage were opened, they were likely satisfied with those answers. The final answers, then, came from WebMD.com.

In regard to symptoms, the information the participant found is similar to that of the Merck manual, although not in as much detail.⁶ As with Merck, WebMD states that symptoms do not appear early on in the disease and that when the disease progresses, weak bones, back pain, loss of height and stooped posture, a curved upper back, and fractures resulting from minor injuries occur.

As for prevention, WebMD provides detailed information regarding bone thinning after age 30, physical activity as a child and teenager, and the necessity of ingesting enough calcium and vitamin D. The site then provided more detailed information about the amount of nutrients and exercise that are needed. WebMD outlines the amount of calcium a person needs per day (this information is different than Merck's), and breaks it down by gender and age group. The same is done for vitamin D. WebMD also outlined the types of exercises that are beneficial, and advises that people not drink alcoholic beverages or smoke. There is no mention of medications.⁷

⁶ <http://www.webmd.com/hw/osteoporosis/hw131453.asp>.

⁷ <http://www.webmd.com/hw/osteoporosis/hw131609.asp>.

Interestingly, this person started their search by looking at the resources available at the London Public Library (LPL), and got there by going to the “Other Libraries” link available on the UWO Library webpage. However, no answer was found using the LPL website because the participant was asked for their library card number before entering any of the databases. Either this person did not have a library card, did not have it with them, or did not realize this information would be required. The participant then went to the UWO Library page and searched through their resources. No answer was found using this resource. For each library, the participant dug down through available links, but did not perform their own search. This person tried two different library webpages, yet neither was of much help. He or she abandoned their search at the Western library page after 4:12, and then went to Google.com to do a search.

During this participant’s search, they continually checked out the reliability of the information by clicking on the “About Us” button at several websites. Perhaps this is why this person started their search by going to a library webpage; he or she was concerned about the reliability of the information. As well, this person altered their search strategy during their session. Once at Google, the participant started with a general search of osteoporosis, later adding the qualifier “symptoms.”

Other C

Question: Prostate Cancer
Session time: 11:54
Resources provided?: No
Websites visited: 7
Pages visited: 34

This person found prostate cancer treatment information at the Canadian Cancer Society website. He or she found this information early on in the search (starting at roughly 4:04), but continued to search for more information before going back to the same treatment page at about 9:04.

The Merck answer, outlined in Appendix 3, gives detailed information about treatment—strategies involved, types of treatment that can be used, etc. The information

the person found gave quite detailed information, but not as detailed as Merck. The first treatment page the person found stated that the doctor determines the treatment that is necessary depending on the stage of the cancer. The site mentions that if it is very early on and the cancer is slow-growing, watchful waiting may be recommended, although they do not go into great detail of what watchful waiting entails. There is no mention of curative treatment or palliative therapy. The Canadian Cancer Society provides information on active treatment, which includes surgery, radiation therapy, and hormone therapy.⁸

Participant Other C then opened the link at the bottom of the page to get more information on treatment options that are available for those living with prostate cancer.⁹ Here, the Canadian Cancer Society goes into more detail about surgery, radiation, and hormone therapy. However, very limited information is provided. For example, under surgery, this is all the information provided: "An operation to remove the prostate. A decision to have surgery depends on the grade and stage of the cancer and the state of your health. Prostate cancer surgery is called a radical prostatectomy." This is surface information to say the least. The Society arguably provides the same amount of information regarding hormone and radiation therapy, but also offer links to pages about side effects. As well, they offer a link to learn more about radiation therapy, which the person did click on.¹⁰ On this page, the Society offers more information on radiation therapy and provided links to learn more about the three types of therapy, but the person did not click on these links.

Finally, the person went back to the page that detailed surgery, radiation, and hormone therapy. He or she then clicked on the side effects link under hormone therapy. Here, the organization discusses the possibility of impotence and incontinence with all types of treatments, not just hormone treatment.¹¹ While they do provide information on the side effects of treatment, they do not do so to the great detail as Merck.

⁸ http://www.cancer.ca/ccs/internet/standard/0,3182,3172_10175_273170_langId-en,00.html.

⁹ http://www.cancer.ca/ccs/internet/standard/0,3182,3172_10175_756275820_langId-en,00.html.

¹⁰ http://www.cancer.ca/ccs/internet/standard/0,3182,3172_369269_langId-en,00.html.

¹¹ The link, then, seemed to be mislabelled. The user is lead to believe that they would find information on side effects from only the hormone treatment, not all treatments.

This person started their search by going to Google and searching for a specific resource—Health Canada. The participant knew of a resource, and went to that resource immediately. Other than the original search for Health Canada, this person found all their information by following the links the different webpages provided.

As mentioned above, this person originally visited these pages starting at 4:04. A number of other searches were conducted before the person returned to the same pages starting at 9:04. The searches made during that period had to do with supportive care. The person was looking up information on support groups and what organizations are available in London. They then looked at different publications that are available from the Public Health Agency of Canada. This person, then, was looking for extra information. Even though participants were instructed to stop their search when they found the right answer, Other C decided to keep looking for more information.

Other D

Question: Prostate Cancer
Session time: 9:50
Resources provided?: Yes
Websites visited: 7
Pages visited: 26

The first resource was NHS Direct Online. The participant found an answer on this resource quickly, before the two minute mark. After completing a search, they found the same answer as the investigators.¹²

The second resource was Google Health. The person found treatment information at the Mayo Clinic website. He or she found information as detailed as the investigators. The Mayo Clinic webpage discussed the different types of treatment available, including radiation, hormone therapy, radical prostatectomy, chemotherapy, cryotherapy, and watchful waiting. The information provided is quite thorough.¹³

¹² <http://www.nhsdirect.nhs.uk/articles/article.aspx?articleId=82§ionId=19142>.

¹³ <http://www.mayoclinic.com/health/prostate-cancer/DS00043/DSECTION=8>.

The last resource was MSN.com. The participant conducted a search, and found an answer at the American Cancer Society concerning treatment.¹⁴ This site goes into great detail about watchful waiting, surgery, radiation therapy, cryosurgery, hormone therapy, orchiectomy, chemotherapy, how to treat the pain and other symptoms, and so forth. The site also shows a picture of where incisions will be made depending on the type of surgery being done. Also discussed is how a person should decide on the best treatment for them.

Interestingly, after finding an answer, the person then looked at pages entitled "Moving on After Treatment" and "Coping Skills." Perhaps the participant was looking for more information for the patron. They may have also been interpreting the question differently than the investigators intended. This person may have believed that the question as posed could mean what the patron should expect to happen after the husband received treatment or how the person will be able to cope with going through the treatment.

Other E

Question: Alzheimer's
Session time: 10:24
Resources provided?: Yes
Websites visited: 4
Pages visited: 21

For the first resource, MediResource, the person found the same answer as the investigators (Appendix 10). The person found information on symptoms, diagnosis, and treatment. For diagnosis, MediResource provides information that states that diagnosing Alzheimer's disease is more about eliminating other diseases and conditions before declaring a person has Alzheimer's. The site also lists ten warnings signs from Alzheimer's Society of Canada. As for treatment, they state that there is no cure for Alzheimer's, but that there are medications available to help improve the quality of the patient's life.¹⁵

For the second resource, the Canadian Health Network, the person found an answer from the Alzheimer's Society of Canada. The person spent time on a page outlining common

¹⁴ http://www.cancer.org/docroot/CRI/content/CRI_2_2_4X_How_Is_Prostate_Cancer_Treated_36.asp?sitearea.

¹⁵ http://mediresource.sympatico.ca/disease_detail.asp?disease_id=218&dowhat=accept_disclaimer.

questions about Alzheimer's disease.¹⁶ On this page, there is brief mention that a doctor can assess a person for Alzheimer's, but there is no substantive discussion about diagnosis. Also discussed is the staging of the disease, but there is no list of possible symptoms at the various stages. The person, then, did not find an answer using the second resource. The other pages on this site the participant visited were "What is Alzheimer's" and "About the Alzheimer's Society." The person may have been concerned that the information is coming from a reliable source.

The person then moved on to the final resource, MSN.com. He or she used the health and fitness links provided, instead of conducting a search. The participant found an answer at the MSN Health Centre information page regarding Alzheimer's disease.¹⁷ The person did not click on the link listed to the right-hand side of the page that would have given more detailed information about symptoms, exams and tests, and treatments. The information found was very basic. There is mention of warning signs of Alzheimer's and that as the disease progresses symptoms get worse. Patients will hallucinate, have delusions, and be paranoid. They will become aggressive and will not be able to complete basic tasks (taking a bath, etc.). As for diagnosis, MSN mentions that tests and examinations can be completed; they devote only five lines to diagnosis. As for treatment, only two paragraphs are devoted to it; MSN states that doctors can only treat the conditions that arise (for example depression and paranoia) and not the disease itself. This resource does provide some information, but not in much detail. Therefore, for this resource, the person only partially answered the question.

Through the entire search, this participant used only links provided by the website.

Other F

Question: Alzheimer's

Session time: 9:45

Resources provided?: Yes (the second resource, NIH, would not open, so this participant looked only at two resources)

¹⁶ <http://www.alzheimer.ca/english/disease/faqs.htm>.

¹⁷ <http://health.msn.com/centers/alzheimers/articlepage.aspx?cp-documentid=100063014>.

Websites visited: 5
Pages visited: 36

The first resource this person looked at was Health Canada. The participant found the same information regarding treatment and diagnosis as the investigators.¹⁸ However, they did not actually find information on symptoms. The person did not look through the page long enough to actually show the list of symptoms on the screen. Therefore, only a partial answer was found.

The person's third resource was Yahoo. The participant searched through the Yahoo health information page to find their answer, as opposed to conducting a search using personal search terms. Digging through the health links, the participant found two articles that help answer the question. One of the articles discussed the various symptoms of Alzheimer's disease.¹⁹ At this page, they state that mild memory problems can eventually turn into Alzheimer's. Examples of regular forgetfulness are provided, contrasted with examples of memory loss caused by Alzheimer's. The sites states that "Alzheimer's disease also causes changes in thinking, behaviour, and personality. Early in the disease, the person may still behave appropriately in social situations, leading others to believe that the person is not ill." They then list ten warning signs listed by the Alzheimer's Association, and state that symptoms include delusions, hallucinations, lack of interest, withdrawal, purposeless activity, aggression, and inability to control impulses.

Participant Other F then looked at information regarding when to see a doctor.²⁰ A person should see a doctor if certain symptoms occur suddenly, memory loss interferes with the person's work or life, or if the person is known to have Alzheimer's and there is a sudden change in behaviour. The participant did not find any information on treatment or diagnosis; therefore, only part of the answer was found.

This participant may have interpreted the question to mean "how do I know if they have Alzheimer's, and should I take them to see a doctor?" If this is the case, then the

¹⁸ http://www.naca-ccnta.ca/position/23_alzheimer/index.htm.

¹⁹ http://health.yahoo.com/topic/alzheimers/symptoms/article/healthwise/hw136643:_ylt=AmEq4zx74OiqOmZHu2KpmCDbtMUF.

²⁰ http://health.yahoo.com/topic/alzheimers/symptoms/article/healthwise/uf4990:_ylt=Ah5TilzhVZbl8sPQt3iZGrLbtMUF.

person found the answer they were looking for using the third resource. This person used links to find the information.

Other G

Question: Alzheimer's
Session time: 7:53
Resources provided?: Yes
Websites visited: 4
Pages visited: 19

The person found their answer using the first resource, Mayo Clinic, very quickly. The participant went to a page that was an interview with a doctor.²¹ Here, the doctor discusses the symptoms and signs of Alzheimer's, how Alzheimer's is diagnosed, and the importance of diagnosis. There is only one question about treatment, and it is dealt with very briefly. The answer here, though, is not the same answer the investigators found. The investigators found quite detailed information on signs and symptoms, diagnosis, and treatment. The participant's answer does not provide as much detail.

The second resource was the Nova Scotia Health Network. He or she conducted a search for Alzheimer's disease, and one of the resulting links was from the Alzheimer's Association. They found their answer on this website, clicking on a page outlining the warning signs of the disease:

1. Memory loss. Forgetting recently learned information is one of the most common early signs of dementia. A person begins to forget more often and is unable to recall the information later.

What's normal? Forgetting names or appointments occasionally.

2. Difficulty performing familiar tasks. People with dementia often find it hard to plan or complete everyday tasks. Individuals may lose track of the steps involved in preparing a meal, placing a telephone call or playing a game.

What's normal? Occasionally forgetting why you came into a room or what you planned to say.

3. Problems with language. People with Alzheimer's disease often forget simple words or substitute unusual words, making their speech or writing hard to understand. They may be unable to find the toothbrush, for example, and instead ask for "that thing for my mouth."

²¹ <http://www.mayoclinic.com/health/alzheimers/AZ00017>.

What's normal? Sometimes having trouble finding the right word.

4. Disorientation to time and place. People with Alzheimer's disease can become lost in their own neighborhood, forget where they are and how they got there, and not know how to get back home.

What's normal? Forgetting the day of the week or where you were going.

5. Poor or decreased judgment. Those with Alzheimer's may dress inappropriately, wearing several layers on a warm day or little clothing in the cold. They may show poor judgment, like giving away large sums of money to telemarketers.

What's normal? Making a questionable or debatable decision from time to time.

6. Problems with abstract thinking. Someone with Alzheimer's disease may have unusual difficulty performing complex mental tasks, like forgetting what numbers are for and how they should be used.

What's normal? Finding it challenging to balance a checkbook.

7. Misplacing things. A person with Alzheimer's disease may put things in unusual places: an iron in the freezer or a wristwatch in the sugar bowl.

What's normal? Misplacing keys or a wallet temporarily.

8. Changes in mood or behaviour. Someone with Alzheimer's disease may show rapid mood swings – from calm to tears to anger – for no apparent reason.

What's normal? Occasionally feeling sad or moody.

9. Changes in personality. The personalities of people with dementia can change dramatically. They may become extremely confused, suspicious, fearful or dependent on a family member.

What's normal? People's personalities do change somewhat with age.

10. Loss of initiative. A person with Alzheimer's disease may become very passive, sitting in front of the TV for hours, sleeping more than usual or not wanting to do usual activities.

What's normal? Sometimes feeling weary of work or social obligations.²²

On this page, the Alzheimer's Association also states that, since the disease progresses so gradually, it is often difficult to tell the difference between normal aging and Alzheimer's. They recommend going to a physician to see if the person's level of functioning is changing.

²² <http://www.alz.org/AboutAD/Warning.asp>.

The participant then went to a webpage on diagnosing Alzheimer's disease.²³ Here, however, the site only gives reasons why a person should be diagnosed. On the next page the participant visited, the Alzheimer's Association discussed the types of tests that are done to diagnose Alzheimer's disease.²⁴ At this page, they state that there is no one test by which to determine if a person has Alzheimer's, but that "diagnostic tools and criteria make it possible for physicians to make a diagnosis of Alzheimer's with an accuracy of about 90 percent." They list tests such as brain scans, laboratory tests, psychiatric evaluation, tests of the nervous system, motor skills tests, and so forth. The Alzheimer's Association does not mention anywhere that an autopsy is needed to confirm that a person had Alzheimer's when alive. The participant also looked at a page regarding available treatment options.²⁵ They only mention that there is no cure for Alzheimer's, but that there may be ways to treat the cognitive and behavioural symptoms. The participant then looked at a page about treating behavioural and psychiatric symptoms.²⁶ At this page, the Alzheimer's Association goes into great detail about available medical and non-medical treatments. Compared to the answers the investigators found, the participant found equivalent information.

Finally, for the last resource, the participant did a search in Google.ca for "Alzheimer's symptoms," restricting the search to Canada. The person found their answer at the Alzheimer Society of Canada. An answer to symptoms and diagnosis was found, although not to treatment. For symptoms, they found the following information:

To help you know what warning signs to look for, the Alzheimer Society has developed the following list:

1 **Memory loss that affects day-to-day function.** It's normal to occasionally forget appointments, colleagues' names or a friend's phone number and remember them later. A person with Alzheimer's disease may forget things more often and not remember them later, especially things that have happened more recently.

2 **Difficulty performing familiar tasks.** Busy people can be so distracted from time to time that they may leave the carrots on the stove and only remember to serve them at the end of a meal. A person with Alzheimer's

²³ <http://www.alz.org/AboutAD/Diagnosis.asp>.

²⁴ <http://www.alz.org/AboutAD/Diagnosis/Test.asp>.

²⁵ <http://www.alz.org/AboutAD/Treatments.asp>.

²⁶ <http://www.alz.org/AboutAD/Treatment/Behavioral.asp>.

disease may have trouble with tasks that have been familiar to them all their lives, such as preparing a meal.

3 **Problems with language.** Everyone has trouble finding the right word sometimes, but a person with Alzheimer's disease may forget simple words or substitute words, making her sentences difficult to understand.

4 **Disorientation of time and place.** It's normal to forget the day of the week or your destination -- for a moment. But a person with Alzheimer's disease can become lost on their own street, not knowing how they got there or how to get home.

5 **Poor or decreased judgment.** People may sometimes put off going to a doctor if they have an infection, but eventually seek medical attention. A person with Alzheimer's disease may have decreased judgment, for example not recognizing a medical problem that needs attention or wearing heavy clothing on a hot day.

6 **Problems with abstract thinking.** From time to time, people may have difficulty with tasks that require abstract thinking, such as balancing a cheque book. Someone with Alzheimer's disease may have significant difficulties with such tasks, for example not recognizing what the numbers in the cheque book mean.

7 **Misplacing things.** Anyone can temporarily misplace a wallet or keys. A person with Alzheimer's disease may put things in inappropriate places: an iron in the freezer or a wristwatch in the sugar bowl.

8 **Changes in mood and behaviour.** Everyone becomes sad or moody from time to time. Someone with Alzheimer's disease can exhibit varied mood swings -- from calm to tears to anger -- for no apparent reason.

9 **Changes in personality.** People's personalities can change somewhat with age. But a person with Alzheimer's disease can become confused, suspicious or withdrawn. Changes may also include apathy, fearfulness or acting out of character.

10 **Loss of initiative.** It's normal to tire of housework, business activities or social obligations, but most people regain their initiative. A person with Alzheimer's disease may become very passive, and require cues and prompting to become involved.²⁷

The participant then went to a separate page on diagnosis.²⁸ The organization states that it is important to be diagnosed so people can make arrangements for their future and to start treatment. Alzheimer's is diagnosed through a series of assessments, including looking at the person's medical history, conducting various medical exams, physical exams, laboratory tests, CT scans, MRIs, PET scans, and psychiatric evaluations. The participant did not find any information on treatment. Therefore, the question was only partially answered.

Here, the person to find their answers fairly quickly. They also sought extraneous information. For example, he or she went to pages that had message boards and forums,

²⁷ <http://www.alzheimer.ca/english/disease/warningsigns.htm>.

²⁸ <http://www.alzheimer.ca/english/disease/diagnosis.htm>.

announcements, and so forth. The participant used a mix of their own search strings as well as using the links provided in order to find an answer. This person was also one of the few participants who narrowed their search to Canadian websites.

CHI Time One A

Question: Osteoporosis
Session time: 6:44
Resources provided?: No
Websites visited: 5
Pages visited: 12

This participant began by going to Google and typing in "pubmed." Obviously, a particular resource was in this person's mind. They did not seem to know which hit to click on, and clicked on a few different hits on the Google results page. Once the correct PubMed website was found, they clicked on "Consumer Health". The participant was taken to Medline Plus.

This participant did not find an answer to the part of the question regarding symptoms. The participant looked at pages entitled "The Low Down on Osteoporosis: What we Know and What we Don't," and "Bone Density Test: Measure your Risk of Osteoporosis." However, neither page gave information on symptoms. The participant did, however, find an answer to the prevention part of the question. In Medline Plus, he or she clicked on a link that took them to a page from the National Osteoporosis Foundation on prevention. This is the same information that was found by participant Other A above.

This person only examined information that was available from Medline Plus. The participant started the session by using their own search, and once they got to certain pages began using the links provided. This person did not seem to look for any extraneous information; this person's search was very straightforward and focused. They knew of a particular resource and then focused entirely on that resource.

CHI Time One B

Question: Osteoporosis
Session time: 23:08
Resources provided?: No

Websites visited: 8
Pages visited: 26

This participant's session was the longest of all the participants at 23:08. Although a time limit of 20 minutes was given, the investigator who was monitoring this session was helping another person and therefore this participant went over the time allotted. The participant found an answer to the prevention part of the osteoporosis question, but not to the symptom part. The participant seemed to focus entirely on prevention. As well, information was found on prevention three separate times, but the participant continued to search for prevention information. The sense from the person's search is that they did not realize an answer to the prevention part of the question had been found. All three answers are discussed below, as the person searched for nearly ten minutes after finding one of the answers, and because the person did not seem sure about the answers.

The first prevention answer came in a document from the National Institutes of Health Consensus Development Program. This document discusses prevention, diagnosis, and treatment of osteoporosis. There is a great deal of information about treatment. This site discusses how most bone building is done within the first 30 years of life, and that physical activity early in life can be beneficial to bones. As for specific prevention, general good nutrition is important; the site goes into detail on the amount of calcium required for a person depending on gender and age. For adults, they should have 1,000 to 1,500 mg per day. Merck said 1,500 mg of calcium per day is needed. There is, then, a slight discrepancy. Also discussed is why vitamin D is so important, and recommendations are given for an appropriate daily amount. The amounts are similar to Merck, but are still lower. They recommend 400-600 IU per day, while Merck recommends 400-800 IU per day. They also discuss how other nutrients such as sodium, phosphorous, and caffeine affect the bones.²⁹

As for exercise, this page states that weight-bearing exercises are beneficial for people of all ages. The site also discusses gonadal steroids and growth hormones as they

²⁹ <http://consensus.nih.gov/2000/2000Osteoporosis111html.htm>.

have an affect on bone health. Not discussed, however, are drugs or estrogen replacement therapy.

The second place the person found an answer was from the National Osteoporosis Foundation. This is the same answer as that of participant Other A.³⁰

The last answer came from EndocrineWeb.com. They state that regular exercise ought to be preformed 30 minutes at a time, three to five times a week. Merck did not provide such exact information about exercise. However, EndocrineWeb.com does not mention that weight-bearing exercises should be done, just exercise in general. As for calcium and vitamin D, the site states that both are necessary but they do not say how much a person should ingest per day. They also mention that hormone treatment, including estrogen, is important, but do not go into any detail.³¹

This person's search seemed unorganized. He or she did not conduct a search for symptoms, but did perform a search for diagnosis and prevention. This person examined general websites, as well as scholarly articles. He or she also clicked on sponsored links, which few other participants did. The person regularly clicked on buttons that would lead them to information about the organization. Perhaps they were making sure the information was reliable, but the sense is that they really did not know where to look for the information. On pages where answers were found, this person did not look to find information about the organization. This person looked at images, information for professionals, biographical information on doctors, disclaimers, programs, resources, and searched for information specifically from Canada.

There were also great chunks of time where the cursor was not moving, indicating the person was likely reading the information presented on the page or rereading the question. Every participant took time assessing the information, but this participant took a longer time than most.

³⁰ <http://www.nof.org/prevention/index.htm>.

³¹ <http://www.endocrineweb.com/osteoporosis/treatment.html>.

CHI Time One C

Question: Alzheimer's
Session time: 9:03
Resources provided?: No
Websites visited: 3
Pages visited: 13

For symptoms of Alzheimer's, the person found this answer on the National Institute on Aging website.³² Here, the user is told the first symptom is mild forgetfulness, but that this is often confused with just growing older. Then they state that "in the early stage of AD, people may have trouble remembering recent events, activities, or the names of familiar people or things. They may not be able to solve simple math problems. Such difficulties may be a bother, but usually they are not serious enough to cause alarm." This is very similar to the information from Merck. As with Merck, the site also goes on to describe what happens as the disease progresses:

Forgetfulness begins to interfere with daily activities. People in the middle stages of AD may forget how to do simple tasks like brushing their teeth or combing their hair. They can no longer think clearly. They can fail to recognize familiar people and places. They begin to have problems speaking, understanding, reading, or writing. Later on, people with AD may become anxious or aggressive, or wander away from home. Eventually, patients need total care.

This resources gives most of the same information as Merck. They also outline seven warning signs of Alzheimer's. These include

1. Asking the same question over and over again.
2. Repeating the same story, word for word, again and again.
3. Forgetting how to cook, or how to make repairs, or how to play cards — activities that were previously done with ease and regularity.
4. Losing one's ability to pay bills or balance one's checkbook.
5. Getting lost in familiar surroundings, or misplacing household objects.
6. Neglecting to bathe, or wearing the same clothes over and over again, while insisting that they have taken a bath or that their clothes are still clean.
7. Relying on someone else, such as a spouse, to make decisions or answer questions they previously would have handled themselves.

Merck also gives examples, although not this many or in this detail.

³² <http://www.nia.nih.gov/Alzheimers/AlzheimersInformation/Symptoms/>.

As for diagnosis, the person found this information at the Alzheimer's Association website. Merck states that there is no way to officially diagnose Alzheimer's until the person in question has past away; doctors can then do an autopsy on the brain to find out if the person did have Alzheimer's. On the page the participant looked at, the Alzheimer's Association does not actually say this; they state that it is important to go to the doctor in order to rule out other diseases and to begin to understand the disease, but does not actually say that there is no way to diagnose Alzheimer's.³³

Regarding treatment, the person found an answer at the National Institute on Aging.³⁴ Here, the Institute states that there is no cure for Alzheimer's, but that there are drugs that may help slow down the progress of the disease, although only for a limited time (Merck states that such drugs only slow the progression of the disease by six to nine months). The Institute also mentions that some drugs may be useful to control some of the behavioural symptoms of Alzheimer's. They go on to mention some of the new treatments that are being tested and which may be useful in the future.

This participant started out by performing a search on Google. He or she did a general search for Alzheimer's disease, then used hyperlinks to dig for information in the sites visited. At the beginning, the participant seemed to seek more general information; for example, "Facts on Alzheimer's Disease." The participant then narrowed the search strategy to the issues of "symptoms," "diagnosis," and "treatment." At one point, the participant spent one minute and twenty seconds looking at one page, yet there was no indication that they found an answer to the question on this page. This person's search seemed relatively straightforward, although they could have likely found the answer to the question in the same site instead of looking at two different sites. Perhaps he or she was trying to make sure they found information from a variety of sources, and did not want to limit their search to the information from just one site.

³³ <http://www.alz.org/AboutAD/Diagnosis.asp>.

³⁴ <http://www.nia.nih.gov/Alzheimers/AlzheimersInformation/Treatment/>.

SECOND ROUND OF TESTING

All 13 LIS 584 participants who took part in the first round of testing also agreed to take part in the second round of testing. Although all the participants were told how to turn on the Camtasia software, one participant did not turn it on; therefore, only 12 sessions were recorded. Information on each of the sessions is provided below.

CHI Time Two A

Question: Menopause
Session time: 6:48
Resources provided?: No
Websites visited: 3
Pages visited: 12

This participant began their search by going to the UWO Library page. The participant was able to click on links under "Resources by Subject" in order to find the information for which they were searching. In this instance, using the library webpage lead the person to the information.

This person found an answer on an American government website. Through links from the Western libraries page, he or she went to womenshealth.gov, a website managed by the U.S. Department of Health and Human Services. At the page regarding the treatment of menopause,³⁵ the department states that hormones and soy food products can assist with reducing hot flashes. However, this page is about treatment for menopause in general, not specifically hot flashes; the information provided about hot flash treatments is rather shallow and not at the same level as the Merck information. The Department also mentions that taking hormones increases a woman's chances of having a heart attack or stroke, so these should be taken under the advice and supervision of a doctor. They also say that postmenopausal women should not take hormones because of these risks.

The information this person found was insubstantial. Although the participant did find an answer, it would not have given the patron all the information they needed, at least according to Merck. Regarding the search, CHI Time Two A did start out searching the UWO

³⁵ <http://4women.gov/menopause/treatment/>.

Library website. However, it took them some time to find a site they thought was useful. He or she had to click on several links before a link specifically on women's health was found. But once this link was found, it did not take the participant long to find what they considered to be the answer.

CHI Time Two B

Question: Menopause

Session time: 6:42

Resources provided?: Yes

Websites visited: 4

Pages visited: 13

The person began with the first resource given, MedBroadcast. The participant conducted a search within the site for "menopause" and "hot flashes," then used the links the website provided at the left-hand side of the page. The participant came to a page on menopause that offered several links to various articles. He or she clicked on a link to one of the articles; this is where they found an answer.³⁶ This article discusses how exercise may help alleviate hot flashes; however, this is not an authoritative article, it is a newspaper article. As well, it only discusses exercise, not other treatments. The answer found by the investigators discussed treatments for menopause generally, without a mention of hot flashes. Because of this, the person cannot be said to have fully answered the question.

The person then moved on to the second resource, the Nova Scotia Health Network. The investigators did not find an answer on this site as all queries seemed to lead to commercial sites trying to sell a product. The participant also did not find an answer. The participant completed a short search but gave up looking for an answer after approximately two and a half minutes. All results seemed to be commercial websites.

The person then went to their last resource, Ask.com. The participant did a very specific search: "menopause hot flashes control." He or she clicked on the first link, which was from MedlinePlus.³⁷ A list of different links was presented (this page did not actually

³⁶ http://www.medbroadcast.com/channel_health_news_details.asp?news_id=10102&channel_id=2013&relation_id=0.

³⁷ <http://www.nlm.nih.gov/medlineplus/menopause.html>.

give any substantive information); the participant hovered over some of the links but did not chose any of them. They did not find an answer using Ask.com.

This participant used a very narrow search for each resource. At times he or she broadened their search in order to get more results, but they did not find an answer to the question using any resource. The first resource provides the closest answer, but this is a newspaper article and is thereby not authoritative. As for the second resource, although the investigators did not find an answer either, the participant only spent two and a half minutes searching there. The participant could have likely found an answer in the last resource, but decided not to continue with their search. This person either thought an answer had been found, or wanted to finish the session quickly.

CHI Time Two C

Question: Ear Infections
Session time: 10:41
Resources provided?: Yes
Websites visited: 4
Pages visited: 27

This participant's first resource was MediResource. They used links available on the page to find their answer. The participant found the same information as the investigators on a page on treatment and prevention of ear infections.³⁸

The second resource was the National Institutes of Health. Here, the participant found the same answer as the investigators, although by a different route. They found an answer to the question at the National Institute of Deafness and Other Communication Disorders webpage.³⁹

For the last resource, the participant used MSN.com. He or she completed a search for "children ear infection." They clicked on a hit from the Mayo Clinic. Searching through the page, the participant found the exact same information as the investigators on ear infections.⁴⁰

³⁸ http://www.mediresource.sympatico.ca/earhealth/infection.asp?channel_id=165&menu_item_id=367&which=5.

³⁹ <http://www.nidcd.nih.gov/health/hearing/otitism.htm>.

⁴⁰ <http://www.mayoclinic.com/health/ear-infections/E199999/PAGE=E100013>.

This person found the same answers for all three resources as the investigators. However, he or she found the answers using a different strategy. The investigators searched for information in each resource; participant CHI Time Two C used only the links provided. However, they were successful in answering the question with all three resources.

CHI Time Two D

Question: Osteoporosis
Session time: 5:07
Resources provided?: No
Websites visited: 2
Pages visited: 11

The participant was able to find information on the prevention of osteoporosis, but not the symptoms. The answers were found at MayoClinic.com. Regarding the prevention of osteoporosis, the Mayo Clinic information focused mainly on calcium and vitamin D, but discussed other ways to prevent osteoporosis as well.⁴¹ The Mayo Clinic states that premenopausal and postmenopausal women who take hormone therapy need at least 1,200 mg of calcium a day, as well as 400 IU of vitamin D per day. "Postmenopausal women not using HT, anyone at risk of steroid-induced osteoporosis, and all men and women over 65 should aim for 1,500 mg of calcium and at least 800 IU of vitamin D daily." These amounts differ slightly from the information in the Merck Manual. The Mayo Clinic goes on to talk about which foods a person should eat and supplements a person should take to get the request amount of calcium and vitamin D. Not provided are the amounts of calcium and vitamin D a person who does not fit into one of the above categories ought to ingest per day.

The Mayo Clinic also states that exercise is a good way to slow bone loss and to build new bone. They give examples of what exercises are weight-bearing, and which exercises will not help build bone. They also discuss adding soy to one's diet, hormone therapy, and avoiding alcohol, smoking, and caffeine.

⁴¹ <http://www.mayoclinic.com/health/osteoporosis/DS00128>.

The person also looked for information on symptoms. From the prevention of osteoporosis webpage, the participant went back to the list of diseases and conditions. The participant then clicked on a link that led them to a "symptoms checker."⁴² At this page, a user can click on a symptom, chose different qualifiers, and possible causes of the symptom are given. The participant did not find the symptoms on osteoporosis. Interestingly, in the same area where they clicked on a link to find the information on prevention, information on symptoms was to the left. The person simply had to click on a link next to the previous link to find the answer. There was a lack of proper assessment with this page.

This participant was not given any resources, but knew of a resource to use. He or she immediately went to Google and did a search for Mayo Clinic. The participant obviously had a resource in mind. Other than the initial search for Mayo Clinic and one search for osteoporosis at the Mayo Clinic page, links were used to find the information. As well, for two periods, totalling 44 seconds, there was no cursor movement. Considering this session lasted barely more than five minutes, this is a long period of time. The person may have been assessing the websites; however, he ore she missed the link that would have given them the answer to the symptoms of osteoporosis. A full answer to the question was not found.

CHI Time Two E

Question: Osteoporosis
Session time: 13:03
Resources provided?: Yes
Websites visited: 9
Pages visited: 34

For the first resource, NHS Direct, the person found the same answers as the investigators, although a different route was used. The participant found both the symptoms of the disease⁴³ and information on how to prevent osteoporosis from developing.⁴⁴

⁴² <http://www.mayoclinic.com/health/symptom-checker/DS00671>.

⁴³ <http://www.nhsdirect.nhs.uk/articles/article.aspx?articleId=271§ionId=17339>.

⁴⁴ <http://www.nhsdirect.nhs.uk/articles/article.aspx?articleId=271§ionId=17344>.

The second resource used was the Canada Health Portal. The participant found their answer to the question from the Osteoporosis Canada Website. The participant examined a webpage which discussed diagnosis,⁴⁵ then looked at webpages discussing exercise requirements and calcium needs⁴⁶. None of the pages in this site actually state what the symptoms of osteoporosis are or how one can prevent it. The investigators scrutinized this webpage, but determined that the information found here does not adequately answer the question. Therefore, the person did not answer the question using this resource.

The last resource used was Google.ca. The participant completed a search for "osteoporosis diagnosis prevention" but did not find their answer. Interestingly, the participant modified their search to "osteoporosis Mayo." They were searching for a specific resource to use. He or she found the Mayo Clinic information on osteoporosis and found their answer on this site. The participant looked at both symptoms⁴⁷ and prevention.⁴⁸ The information contained in these two pages answer the question posed.

Another interesting aspect of the search in Google was that the person, before looking specifically for the Mayo Clinic, clicked on a link for the Merck Home Manual. They looked at this information quickly but then went back and continued their search. The person seemed bent on looking for information from the Mayo Clinic.

CHI Time Two F

Question: Osteoporosis

Session time: 10:57

Resources provided?: Yes

Websites visited: 8

Pages visited: 27

⁴⁵ <http://www.osteoporosis.ca/english/About%20Osteoporosis/Diagnosis/default.asp?s=1>.

⁴⁶ <http://www.osteoporosis.ca/english/About%20Osteoporosis/Physical%20Activity/default.asp?s=1>,
<http://www.osteoporosis.ca/english/About%20Osteoporosis/Nutrition/default.asp?s=1>.

⁴⁷ <http://www.mayoclinic.com/health/osteoporosis/DS00128/DSECTION=2>.

⁴⁸ <http://www.mayoclinic.com/health/osteoporosis/DS00128/DSECTION=9>.

For the first resource, Healthy Ontario, the person found the same information as the investigators, although through a different route. The participant's answer for symptoms and prevention of osteoporosis is found on the same webpage.⁴⁹

The second resource used was the Yahoo Canadian Health Directory. In this directory, the participant found their answer from the International Osteoporosis Foundation. They looked at diagnosis and prevention, but did not find any information on symptoms. Under diagnosis, the IOF outlines the various risk factors for osteoporosis, but do not discuss symptoms.⁵⁰ The IOF goes on to discuss the types of diagnostic tools that are available. Participant CHI Time Two F also clicked on a link entitled "What is Osteoporosis."⁵¹ Here, the IOF states that there are often no symptoms of the disease at first, and that the first sign of osteoporosis is a broken bone. As for prevention, the IOF discusses what people can do in both childhood and adolescence to ward off osteoporosis. For adults, the IOF goes into detail about calcium and vitamin D. They also state the amount of calcium a person needs depending on their age and gender, and list example foods and how much calcium each contains.⁵² The IOF also discusses the need for weight-bearing exercise. While the participant considered this the best answer using the Yahoo Canadian Health Directory as a resource, they only found a partial answer using the IOF. The person did not find any information on symptoms, and the prevention information is scant on vitamin D.

The last resource the person used was Google. A number of searches were completed and an answer was found at the Cedars-Sinai website. They discuss symptoms thusly:

Osteoporosis is a condition that has virtually no symptoms until severe bone damage has already occurred. Once the bones have been weakened by bone density loss, symptoms may include:

- Back pain

⁴⁹ <http://www.healthyontario.com/Conditions/O/Osteoporosis.htm>.

⁵⁰ <http://www.osteofound.org/osteoporosis/diagnosis.html>.

⁵¹ http://www.osteofound.org/osteoporosis/about_osteoporosis.html.

⁵² <http://www.osteofound.org/osteoporosis/prevention.html>.

- Loss of height over time with stooped posture
- Fractures of the vertebrae, wrists, hips or other bones

Without treatment, a person with osteoporosis is likely to have fractures, most often in the spine or hips (which support the body's weight) or in the wrists from bracing against a fall. Fractures of the spine can happen even without a fall or an injury. The bones of the spine become so weak that they start to compress. These types of fractures can cause severe pain and require a long recovery period. They also cause a loss of height and stooped posture.

Hip fractures, the second most common type of fracture due to osteoporosis, usually result from a fall. Although most people do relatively well with modern surgical treatment, hip fractures can result in disability and even death from postoperative complications.⁵³

As for prevention, the site discusses the importance of calcium and vitamin D, and even provide the amounts of each a person should ingest each day. They go on to state the need for weight-bearing exercise. Cedars-Sinai also states that people should not smoke, limit alcohol and caffeine, and consider hormone therapy. The information provided by this resource is detailed; therefore, the person was able to answer the question using Google.ca.

It was interesting that this person searched through each resource at the same time. Often, when one page was downloading, the person would go to the next resource to search for information or click on a link; when that page was downloading, the person would go to the next resource and so forth. No other participant conducted their search this way.

CHI Time Two G

Question: Prostate Cancer
Session time: 16:20
Resources provided?: Yes
Websites visited: 7
Pages visited: 35

The first resource this person looked at was Health Canada. They spent seven minutes at this site, but they did not find an answer. The participant looked at a couple of articles, but these articles discussed screening and testing. This person spent a good deal of time searching for prostate cancer, and revised their search several times. However, he or she moved on to the next resource without finding any information on treatment.

⁵³ <http://www.csmc.edu/5219.html>.

The next resource was the Google Health portal. The participant looked at the Canadian Cancer Society website, but did not find an answer. He or she looked at general information on what a person needs to know about prostate cancer and information on supportive care. Despite searching on this site for some time, no answer was found.

The participant then moved on the last resource, Yahoo.com. He or she found an answer in this resource. They did a search within the Yahoo health and fitness site. An article entitle "Prostate Cancer: Treatment–Patient Information" was found. Here, there is much detail about treatment, including watchful waiting, surgery, and radiation and hormone therapy.⁵⁴ The site also discusses up-and-coming treatments such as cryosurgery, chemotherapy, biologic therapy, and high-density focused ultrasound. This information is more in depth than the information found by the investigators. The person was able to answer the question using the last resource.

This person's search was quite scattered. They used a combination of their own searches and using links provided by a website. He or she also rethought their search strategy several times; they would often search for one thing, then immediately go back and revise the search. The participant also took a great deal of time to assess a page before deciding to click on a link. For one search, he or she clicked on links for sexual health and promotion. Perhaps the person was trying to cover all the possible terms that could be related to prostate cancer. This person may also have gotten frustrated by not being able to find an answer and was trying any search strategy they could think of. Overall, an answer was not found until after the 15 minute mark.

CHI Time Two H

Question: Alzheimer's
Session time: 7:36
Resources provided?: Yes
Websites visited: 5
Pages visited: 19

⁵⁴

http://health.yahoo.com/topic/prostatecancer/treatment/article/healthwise/ncicdr0000062965:_ylt=AjL6WoBVS39_tahiWriwHdLL7MBE.

The participant's first resource was the Mayo Clinic. He or she found their best answer at the same interview page as participant Other G above.⁵⁵ Here, the doctor discusses the symptoms and signs of Alzheimer's, how Alzheimer's is diagnosed, and the importance of diagnosis. There is only one question about treatment, and it is dealt with very briefly. The answer, though, is not the same answer the investigators found. The investigators found quite detailed information on signs and symptoms, diagnosis, and treatment. The participant's answer does not give as much detail. This person did not, then, find a full answer to the question with this resource.

The second resource was the Canadian Health Network. The participant found an answer to warning signs (symptoms) and diagnosis, but not for treatment. For warning signs, the participant found the ten warning signs from the Alzheimer Society,⁵⁶ listed above under participant Other G. As for diagnosis, at the same website the person found a page dedicated to diagnosing Alzheimer's disease.⁵⁷ The Society states the symptoms of Alzheimer's, why it is important to find out if a person has Alzheimer's, the process of assessment, the tests that will be conducted, how to prepare for the assessment, the family's role in the whole process, what questions to ask, and what supports the person should seek out. As there was nothing found on treatment, the question was only partially answered.

The last resource was MSN. The person conducted a search within the health and fitness portion of MSN. He or she clicked on link for the Alzheimer's Association. Here, a search was conducted and an Alzheimer's disease fact sheet was found. This is where the participant found an answer.⁵⁸ They give information on diagnosis and treatment of Alzheimer's but do not discuss symptoms or signs. Therefore, the participant has only partially answered the question.

⁵⁵ <http://www.mayoclinic.com/health/alzheimers/AZ00017>.

⁵⁶ <http://www.alzheimer.ca/english/disease/warningsigns.htm>.

⁵⁷ <http://www.alzheimer.ca/english/disease/diagnosis.htm>.

⁵⁸ <http://www.alz.org/Resources/FactSheets/FSADFacts.pdf>.

CHI Time Two I

Question: Prostate Cancer

Session time: 8:22

Resources provided?: No

Websites visited: 4

Pages visited: 16

The participant did not find an answer that fits the Merck answer as they seemed to frame the question in their mind different from what was intended. This participant framed the question as more emotional, and tried to find out what the person would be going through mentally, what questions they should ask, and what they should expect the doctor to do. The participant did go to one page discussing side effects, but did not spend as much time on this page as the other pages.

This person found the majority of their answer at the Prostate Cancer Research Foundation of Canada. The first page in what appears to be the person's answer is one entitled "Dealing with the Disease;"⁵⁹ he or she spent a great deal of time on this page considering its length. On this page, the organization states that the person will be going through a wide range of emotions, that patients need to educate themselves about the disease, and that there are support groups that can help. The information on the next webpage visited, "What to Expect,"⁶⁰ concerns the basic information the person will need regarding the grade and stage of the tumour, as well as stage groupings. This is more technical in nature and does not provide any information on treatment.

The next web page looked at was "Chain of Events."⁶¹ Here, the organization outlines the different events that occur once a man has gone for a test and a problem is suspected. This is more about the different steps that will be taken during the diagnosis, treatment, and monitoring phases.

⁵⁹ http://www.prostatecancer.ca/english/prostate_owners_manual/living/dealing/.

⁶⁰ http://www.prostatecancer.ca/english/prostate_owners_manual/living/expect/.

⁶¹ http://www.prostatecancer.ca/english/prostate_owners_manual/living/expect/.

The next page looked at is "Questions to Ask your Doctor."⁶² Here, the organization states that the patient should ask certain questions about their cancer, their chances for survival, the treatment options, and what they should do next.

The participant then looks at a page about testing and symptoms; the query the participant is trying to answer states that the patron's husband has already been diagnosed with prostate cancer, so this page is moot. The next webpage looked at was "What You Should Expect from Your Doctor."⁶³ The participant highlighted a portion of the page with their cursor which discusses how some forms of prostate cancer can be slow moving, so it may be best to forego treatment "to allow an informed discussion to take place between a man, his family and treating physicians." The other part of the highlighted portion discusses getting tested for prostate cancer:

Men should talk with their doctor about the possible benefits and risks of prostate cancer testing. The initial assessment which will include a history of symptoms, family history of prostate disease, prostate-specific antigen (PSA) test and digital rectal examination (DRE), both discussed later, may strongly suggest a prostate problem but a definite diagnosis of prostate cancer can only be made following a prostate biopsy.

This page is focused more on what to consider before getting tested. The participant may not have read the whole page before highlighting it.

After looking at the above pages, the person continued to search. He or she looked at symptoms of prostate cancer and other pages. The participant did spend some time on a page from the Prostate Cancer Foundation about side effects of treatment. The Prostate Cancer Research Foundation of Canada states the following "There are six broad categories of side effects that are typically associated with prostate cancer treatments: urinary dysfunction, bowel dysfunction, erectile dysfunction, loss of fertility, effects due to the loss of testosterone, and side effects of chemotherapy."⁶⁴ This is the extent of the information given. A person can click on each category for more information, but the participant did not do this. Therefore, the person did not find any information that matched the Merck answer.

⁶² http://www.prostatecancer.ca/english/prostate_owners_manual/living/expect/questions/.

⁶³ http://www.prostatecancer.ca/english/prostate_owners_manual/living/testing/expect/.

⁶⁴ http://www.prostatecancerfoundation.org/site/c.itlWK20SG/b.1420081/k.93C6/Side_Effects.htm.

This person found the majority of their answer very early on in their search, starting at 2:01 and ending at about 4:52, but continued to search for other information. It seems that they were trying to find more information for the patron than required. This person started with a Google search, but did not have a specific resource in mind. The participant started their search by typing in “prostate cancer” and clicking on the hits they thought were relevant. For their search, except for the initial search in Google, he or she looked through the sites using the links provided.

CHI Time Two J

Question: Alzheimer’s
Session time: 7:58
Resources provided?: No
Websites visited: 3
Pages visited: 14

The person focused on warning signs of Alzheimer’s (which could be considered symptoms of Alzheimer’s), and when to visit a doctor. The participant conducted a search and found a webpage from the Alzheimer’s Association which provides a list of ten warning signs; this list is reproduced above under participant Other G, who found the same resource.⁶⁵

On this same page, the Alzheimer’s Association states that it is often difficult to tell the difference between normal aging and Alzheimer’s since it happens so gradually. The Association recommend going to a physician to see if the person’s level of functioning is changing.

The participant then focused on when a person should visit a physician.⁶⁶ At this page, the organization states that it is important to go to the doctor early on when a person thinks Alzheimer’s may be setting in. They also give suggestions on what to bring to the appointment (list of symptoms, medications the person is taking, etc.), and what to ask in

⁶⁵ <http://www.alz.org/AboutAD/Warning.asp>.

⁶⁶ <http://www.alz.org/AboutAD/Diagnosis/Visiting.asp>.

regards to the type of testing that will be conducted. Finally, they mention that people can seek help and support from area Alzheimer's organizations.

The person appeared to define the question as "I think my mother may have Alzheimer's. What are the signs? Should I take her to a doctor?" rather than specific questions about symptoms, diagnosis, and treatment. The answer the person found for symptoms does not give the detailed information about how the symptoms progress as time goes on as the Merck answer does, but the warning sign examples do provide much the same type of information Merck does regarding the very early stages of the disease. However, the remainder of the question about treatment and diagnosis went unanswered.

This participant began their search by going to Google. The person used a combination of their own searches plus clicking on links provided in a website. As well, they started with a specific resource. In Google, they did a search for "medline."

CHI Time Two K

Question: Prostate Cancer

Session time: 9:08

Resources provided?: Yes

Websites visited: 6

Pages visited: 18

This person's first resource was MedlinePlus. This person found an answer very quickly (by the two minute mark). He or she conducted a search for "prostate cancer," and found a link to the Prostate Cancer Foundation. Here, he or she clicked on a link for treatment.⁶⁷ This page is an introductory page on treatment; to get more detailed information on specific treatments, the person must click on links to the left-hand side of the page. The participant did not do this; he or she merely looked at this introductory page, which gives the following information:

There is no "one size fits all" treatment for prostate cancer, so each man must learn as much as he can about various treatment options and, in conjunction with his physicians, make his own decision about what is best for him.

⁶⁷ http://www.prostatecancerfoundation.org/site/c.itlWK2OSG/b.70617/k.8235/Prostate_Cancer_Overview.htm.

For most men, the decision will rest on a combination of clinical and psychological factors. Men diagnosed with localized prostate cancer today will likely live for many years, so any decision that is made now will likely reverberate for a long time. Careful consideration of the different options is an important first step in deciding on the best treatment course.

Consultation with all three types of prostate cancer specialists—a urologist, a radiation oncologist and a medical oncologist—will offer the most comprehensive assessment of the available treatments and expected outcomes.

This is very scant information. Therefore, the person did not appropriately answer the question.

Interestingly, after looking at this page, the person examined a page regarding side effects of treatment. The participant may have been searching for extra information for the patron.

The next resource was the National Institutes of Health website. The participant did a search for “prostate cancer,” and found an answer on a page from the National Cancer Institute. The treatment page at this site gives very detailed information on treatment options including getting a second opinion, surgery, radiation, hormone therapy, and watchful waiting.⁶⁸ They also suggest some questions a person should ask their doctor. Detailed information is found on this page.

As with the last resource, this person kept on searching in the same website after finding an answer. He or she went to a page on complementary and alternative medicine, then to a page on follow-up care. The participant is either looking for more information for the patron, or has defined the question to mean something other than the investigators expected.

The final resource used was Ask.com. The person completed a search and found their answer on Prostateinfo.com. Here, he or she again clicked on a link for treatment. However, as with the first resource, the page is more general in nature; to get more information on treatment, the person would have had to click on links located at the left-hand side; the

⁶⁸ <http://www.cancer.gov/cancertopics/wyntk/prostate/page9>.

participant did not click on these links. On the webpage the person looked at,⁶⁹ Prostateinfo.com provides general information on treatments of curative intent and palliative treatment, as well as information on how a treatment method is chosen. Because this is just general information, a full answer was not found.

Again, however, the person looked at other information after they found an answer. He or she looked at a page about giving support to a person who has cancer. This person thought this question involved more than just treatment.

CHI Time Two L

Question: Alzheimer's
Session time: 11:45
Resources provided?: Yes
Websites visited: 3
Pages visited: 40

Beginning at the first resource, MedBroadcast, the person found a page with general information on Alzheimer's. This is the only page that lists any sort of symptoms. Ten warning signs of Alzheimer's are outlined.⁷⁰ There is also information about diagnosis and treatment, but the participant found other pages with more detailed information.

For diagnosis, the person found a page in the MedBroadcast website devoted to that topic. The page starts out with the following: "There is currently no specific clinical test or procedure that can definitively diagnose Alzheimer's disease (AD). AD is therefore considered a diagnosis of exclusion - that is, the many other causes of dementia must be ruled out by thorough evaluation before the clinical diagnosis of AD can be made."⁷¹ They go on to outline what the doctor will look for, what steps will be needed, and the tests that will be used.

The participant also went to a webpage devoted to the treatment of Alzheimer's disease.⁷² It states that Alzheimer's has no cure, but there are medications that can make the person more comfortable. Also stated is that support for the caregiver is important. The

⁶⁹ <http://www.prostateinfo.com/patients/treatment/index.asp>.

⁷⁰ http://www.medbroadcast.com/channel_section_details.asp?text_id=2102&channel_id=1001&relation_id=7156.

⁷¹ http://www.medbroadcast.com/channel_section_details.asp?text_id=1003&channel_id=1001&relation_id=7156.

⁷² http://www.medbroadcast.com/channel_section_details.asp?text_id=1005&channel_id=1001&relation_id=7156.

participant found enough detailed information about Alzheimer's with this resource to be considered to have answered the question.

The second resource was Alberta Health. The investigators did not find an answer from Alberta Health in the first three hits after completing a search. The recipient, however, found an answer. By using a combination of linking and searching, the person ended up at HealthLink Alberta. Here, the participant was able to find a page detailing Alzheimer's disease.⁷³ There is basic information on signs, symptoms and treatment. There is nothing on diagnosis. The participants found enough information to say an answer was found (considering the investigators did not find any answer).

The last resource the person looked at was Yahoo.com. He or she found an answer for symptoms at the same webpage as participant Other F above.⁷⁴ The participant did not find an answer for diagnosis, but did find an answer for the treatment of Alzheimer's disease.⁷⁵ The site discusses that there is no cure for Alzheimer's but that there are treatments to assist the person in maintaining a good quality of life. They go in to great detail about taking certain medications, recognizing when new medical problems arise, and end-of-life care. This is a fairly detailed page. The participant found an answer to the majority of the question, but not in its entirety.

ANALYSIS/DISCUSSION

What pathways do information professionals take when using the Internet to find an answer to a health query?

When searching for answers to a consumer health question, the participants used both their own search strings as well as hyperlinks provided on any particular webpage. The searches ranged from very broad ("osteoporosis") to very narrow ("menopause hot flashes control.") Some participants used the only links available from the webpages of the resources given. Participants who were not provided with specific resources also used links to find answers. Whether a participant used only links or a combination of searches and

⁷³ <http://www.healthlinkalberta.ca/Topic.asp?GUID={9C4FEC65-191A-4A50-A247-8DF0ECC580FE}>.

⁷⁴ http://health.yahoo.com/topic/alzheimers/symptoms/article/healthwise/hw136643:_ylt=AmEq4zx74OIqOmZHu2KpmCDbtMUF.

⁷⁵ http://health.yahoo.com/topic/alzheimers/treatment/article/healthwise/hw136814:_ylt=AoTK5Mu123GKB7kQFAalTz7btMUF.

links did not seem to affect the overall quality of their search. For example, participants who received a list of resources to use often found an answer by using the links provided; conversely, the investigators used their own search string and found the same answer. Of course, a problem with conducting a search is that websites may not index the information or provide access points using the same words or phrases as a user. As well, some users will employ different terms than other users—a nurse will use more technical terms while a consumer will use colloquial speech. Because of this, conducting a search can be problematic. However, by using links a person can usually see how information is indexed and defined, and can work their way down to the information for which they are searching.

For those who did not receive specific resources, almost all used the Google search engine during their session. Overall, of ten participants who searched for an answer to the query using any resource they wished, nine used Google at least once. Even though not all information available on the web is indexed by Google, none of the information professionals used another search engine along with Google (i.e., Yahoo) in order to make sure they canvassed as much of the web as possible. This reliance by information professionals on Google is disconcerting; while Google provides access to much of the information on the web, it does not access everything. One might assume that an information professional would qualify their search with another search engine to make sure they had accessed as much as possible. However, due to the nature of the study, the participants may not have felt comfortable in doing this. They were instructed to stop searching once they found an answer; perhaps they felt that if they looked for the same information in another search engine they would be going outside the parameters of the study. In any event, this points to the fact that many information professionals rely on Google to guide them to the information they are seeking.

Two of the ten participants who did not receive resources used library webpages to find an answer to their assigned question. However, only one participant was able to find an answer using a library-directed source. One participant looked at both the LPL and the UWO

Library webpages. Regarding the LPL, the person kept clicking on links to databases, but their library card number was requested. Either they did not have a library card, did not know their number, or they did not know they would need this information. In any event, the person left the LPL website without finding any answers. This is discouraging as libraries advocate access to information for anyone, not just certain people. Requiring people to input their library card number means there will be many users who are looking for reliable information at the library but will not be able to do so. Of course, the library is doing this so that only those they actually serve have access to the site (i.e., people who are living in Alberta can look at their own local library website). However, it does mean that access has been denied.

As for the UWO Library webpage, of the two participants who used it, only one was able to find information. For the person who did find an answer (Participant CHI Time Two A), it took a good deal of time to find a resource they could use. They initially used the "find" function to look for information on women's health. Only one resource came up. The participant did not believe that resource was helpful, so they continued searching. The difficulty this person had, along with the fact that another participant could not find any resource that was useful, may indicate that the library website needs to be redesigned; it should be easier to find information on a library website.

For the ten participants who did not receive any resources, seven used a specific resource. For example, Other C immediately went to Google and searched for Health Canada. Participants in both the first and second round of testing searched for a specific website. This may indicate just how pervasive consumer health information has become online. Even those participants who had not taken a consumer health information class, or had only attended one class, knew of a resource they would like to use. Considering that the Internet is certainly growing, and even more consumer health information will be available online, people's knowledge of consumer health information websites can only continue to expand.

Regarding the above, what stands out to the investigators is the fact that information professionals seem to have foregone the library website and are relying on the familiar search that Google provides. Whether they use Google to search for a specific resource or use it for their main search, novice information professionals are not using more trusted resources to search for information.

How long does it take for an information professional to find a “best” answer (in both time and number of webpages visited)?

The basic statistics for this question are presented below. A discussion of same continues thereafter.

Participant	Session time	No. of websites	No. of pages
Other A	10:49	5	24
Other B	10:46	6	33
Other C	11:54	7	34
Other D	9:50	7	26
Other E	10:24	4	21
Other F	9:45	5	36
Other G	7:53	4	19
CHI Time One A	6:44	5	12
CHI Time One B	23:08	8	26
CHI Time One C	9:03	3	13
Mean (overall)	11:45	5.4	24.4
Median (overall)	10:07	5	25
Mean (no resources)	12:07	5.65	23.65
Median (no resources)	10:48	5.5	25
Mean (resources)	9:28	5	30.3
Median (resources)	9:48	4.5	23.5

Participant	Session time	No. of websites	No. of pages
CHI Time Two A	6:48	3	12
CHI Time Two B	6:42	4	13
CHI Time Two C	10:41	4	27
CHI Time Two D	5:07	2	11
CHI Time Two E	13:03	9	34
CHI Time Two F	10:57	8	27
CHI Time Two G	16:20	7	35
CHI Time Two H	7:36	5	19
CHI Time Two I	8:22	4	16
CHI Time One J	7:58	3	14
CHI Time Two K	9:08	6	18
CHI Time Two L	11:45	3	40
Mean (overall)	9:33	4.5	20.5
Median (overall)	8:45	4	18.5
Mean (no resources)	7:05	3	13.2
Median (no resources)	7:38	3	13
Mean (resources)	10:47	5.1	23.7
Median (resources)	10:49	5.5	27

Both the mean and median for session time, number of websites visited, and number of pages visited are given. This is important for the session time because there were outliers in each session. During the first round, one participant's session lasted 23:08; the next longest session was 11:54. This outlier skews the mean, which is why the median is helpful. Whether looking at the mean or the median, those who took part in the second round finished their session faster than those in the first round.⁷⁶ As well, those in the second round visited fewer websites and pages than those in the first round. This indicates that, after receiving consumer health information training, information professionals find an answer to a consumer health query in less time and with fewer resources.

During the first round, those participants not assigned resources in which to search had longer sessions than those who searched using assigned resources. This seems to be counterintuitive; one would think that participants who were required to look at three

⁷⁶ Please note that because of the problem with SQUID, there were only three participants from LIS 584 whose data from the first round of testing was included in this study. Because that is such a low number, we are comparing all the participants from the first round of testing against those in the second round of testing.

separate resources would take longer to search than those who only had to use one source. However, the only participants who were assigned resources during round one were not enrolled in LIS 584; perhaps those who were enrolled in LIS 584 would have found answers more quickly because they were more interested in health information, as indicated by their enrolment in a consumer health information class. This, however, requires further study.

As for the second round, those who did not have to search in three specific resources took less time with their session than those who were assigned resources. They also visited fewer websites and much fewer pages. This is not surprising considering they only had to look for an answer once, not three times. It is interesting, however, that those who were not assigned resources took as long as they did in their session; their sessions lasted longer than the investigators expected. The average session time for those who were assigned resources is 3:42 longer than the average session time for those who were not assigned resources. One would assume that if it took an average of 10:47 for those who were assigned resources to find three answers, that those who did not have to use a particular resource would take about a third of that time to find one answer. Those who were not assigned resources may have decided to take their time in their search, or may have looked for extraneous information. The quality of the search, then, becomes important. This is discussed below.

Are information professionals able to find a “best” answer to a consumer health question? Does exposure to training in consumer health information affect whether or not an information professional finds a “best” answer?

Using the Merck Manual and the answers found by the investigators as the “gold standard,” the following are statistics regarding the quality of the answers found:

First Round of Testing					
		Partial Answer	No Answer	Best Answer	
Overall					
	Number	11	1	6	
	Percentage	61.1	.05	33.3	
No Resources					
	Number	5	0	1	
	Percentage	83.3	0	16.7	
Resources					
	Number	6	1	5	
	Percentage	50	.08	41.7	

Second Round of Testing					
		Partial Answer	No Answer	Best Answer	
Overall					
	Number	10	7	11	
	Percentage	35.7	25	39.3	
No Resources					
	Number	3	1	0	
	Percentage	75	25	0	
Resources					
	Number	7	6	11	
	Percentage	29.2	21.4	39.3	

Overall					
		Partial Answer	No Answer	Best Answer	
Overall					
	Number	21	8	17	
	Percentage	45.6	17.4	36.9	
No Resources					
	Number	8	1	1	
	Percentage	80	10	10	
Resources					
	Number	13	7	16	
	Percentage	36.1	19.4	44.4	

Those in the first round found more partial and “best” answers than those in the second round. Overall, however, there were more “best” answers found during the second round than in the first round. Nevertheless, it was more common for participants to find only a partial answer rather than a “best” answer. More participants in the second round found no answer to the question than those in the first round. It seems that after exposure

to a good deal of consumer health information resources, more “best” answers were found. Interestingly, in both rounds of testing, those who were given resources found more “best” answers than those who were not given resources. This is in spite of the fact that most people who did not receive resources searched for information using a specific website about which they knew. The website, portal, or search engine a person decides to use can greatly determine their success in finding an answer.

How can one explain the lack of “best” answers during the second round? Why were there so many sessions with no answer? Some participants seemed to interpret their question differently from what the investigators intended. For example, CHI Time Two I focused on what a person with prostate cancer would be going through mentally. They also focused on information about how to interact with a doctor during this time. Without being able to conduct a proper reference interview, some participants misinterpreted the questions. They did seem to find an answer to the question they believed was asked, so the success rate may arguably be higher than indicated above.

Some partial answers had to do with the fact that the participant did not dig deep enough into the page’s links. Participant CHI Time Two K found a partial answer using their first resource, but could have found the “best” answer if they had clicked on the links presented at the left-hand side of the page. Nicholas et al. call this “bouncing,” meaning those searching online do not penetrate a website in any depth and instead looks at many websites for information. Some participants did not dig deep enough into the websites in order to find a best answer to the question. This seems to be the new way people search for information, as they now search horizontally, not vertically. People want to get their information from more than one website, and therefore do not want to spend too much time on one site searching for information (Nicholas et al.).

In conclusion, the results indicate that those who have received training in consumer health information resources are more likely to find a “best” answer than those who have not received such training. Once an information professional receives training in this area,

they find their information faster and use fewer websites and pages. However, the results also indicate that (novice) information professionals search for information much like the layperson and have not developed their search patterns as effectively as experienced information professionals (Tabatabai and Shore, Nicholas et al., Morahan-Martin). There were more non-answers found during the second round of testing than in the first; even though the participants had exposure to consumer health information resources, they were not able to successfully answer all the questions. This indicates that there was a lack of proper assessment, either of the query presented or the websites examined. This area needs further study, but those who are new to the information profession seem to be holding on to their former search strategies, while at the same time incorporating a better understanding of the resources available.

STRENGTHS AND WEAKNESSES

A strength of this study is that the investigators were able to test those who are interested in consumer health information directly before and after they had received training in this area. As well, because participants at the second testing session were assigned different queries than at their first session, practice effects have not confounded the results. A further strength is that, because the software did not store any personal information about the participants, anonymity and confidentiality were ensured. As mentioned above, a list of participants from LIS 584 and the queries they received during the first session was kept to ensure they did not receive the same question during the second session. That list has since been destroyed.

A weakness is that, due to time constraints, the investigators were not able to ask the participants to reflect on their search processes, or to provide commentary on search tactics. One-on-one interviews, focus groups, and surveys were not possible. As well, because the SQUID software did not provide any meaningful data, the investigators could not use that data for analysis. This limited the amount of data from the first round of testing that could be used to compare against the data which was gathered during the second

round of testing. In future studies, testing the software programs beforehand to ensure they will provide the data required is advisable.

The small number of participants the investigators were able to recruit is also a weakness of the study. More participants taking part in a study allow investigators to gather more information, resulting in data that are more reliable and valid.

Another weakness is that during the first round of testing the participants took part either by themselves or with only one or two other participants, while during the second round all 13 participants were tested at the same time. It would be best to keep the same type of testing environment at the first and second rounds. Perhaps being tested in a group at the end made some participants nervous—they may have seen other participants leaving and felt pressure to finish up and leave as well. This can make one's search sloppy and incomplete. This could have affected the results.

Finally, the second round of testing came during a time when most students in the Masters program are very busy finishing up their classes. They may have been distracted and wanted to finish up quickly so they could go and work on their assignments. In discussions with the professor who taught LIS 584, she noted that the student's answers for a reference question assignment she gave early in the term were better and more complete than the answers for a reference question assignment given later in the term. At the beginning of a school term, there are less assignments and students focus more on their work; however, by the middle of the term, students are often overloaded with work and cannot devote as much time or energy to an assignment. The second round took place with only one month left of school. At this time, students will be knee-deep in assignments and are not able to focus on each assignment in great detail. The participants may not have been able to focus on the questions and answers because their school work was becoming hectic and overwhelming. Stress of this sort can affect how a person does on a test or assignment, and this very well may have affected the results of the second round of testing.

AREAS FOR FURTHER STUDY

This study provided a great deal of useful information. However, because the investigators could not interview or survey the participants, future researchers could extend this study by conducting one-on-one interviews, focus groups, or administering surveys. As well, for this study the investigators used information students as participants. It may be wise to extend the study by using more experienced information professionals to gage how they search websites to find an answer to a health query.

Additionally, it may be useful to expand or change the websites, portals, and search engines to examine how information professionals search through resources that are not as familiar to them. And the consumer health questions could be changed to represent less common ailments. Providing an information professional with a question about a condition they have never heard of or searched for will reveal more about how information professionals search for health information.

Future studies could also expand on this research by recruiting experienced information professionals. Experienced information professionals may search for information differently than novice information professionals; it would be interesting to discover these differences and how they affect one's search for consumer health information online.

Finally, it would be interesting to have a live patron asking the participants the consumer health query. This would allow the information profession to conduct a proper reference interview and understand exactly what the person is looking for.

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Appendix

- 1 Answers – Merck Manual Home Edition – Menopause
- 2 Answers – Merck Manual Home Edition – Osteoporosis
- 3 Answers – Merck Manual Home Edition – Prostate Cancer
- 4 Answers – Merck Manual Home Edition – Ear Infection
- 5 Answers – Merck Manual Home Edition – Alzheimer’s
- 6 Answers – Investigators – Menopause
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- 8 Answers – Investigators – Prostate Cancer
- 9 Answers – Investigators – Ear Infection
- 10 Answers – Investigators – Alzheimer’s

Appendix #1

Query #1: Menopause

How can I control my menopausal hot flashes?

Merck Manual Home Edition (<http://www.merck.com/mmhe/index.html>)
<http://www.merck.com/mmhe/sec22/ch243/ch243a.html#sec22-ch243-ch243a-161>

Treatment

Not consuming spicy foods, hot beverages, caffeine, and alcohol may help prevent hot flashes, because these substances can trigger hot flashes. Eating foods rich in B vitamins or vitamin E or foods rich in plant estrogens (phytoestrogens), such as tofu, soy milk, tempeh, and miso, may also help. Not smoking, avoiding stress, and exercising regularly may help improve sleep as well as relieve hot flashes. Wearing layers of clothing, which can be taken off when a woman feels hot and put on when she feels cold, can help her cope with hot flashes. Wearing clothing that breathes, such as cotton underwear and sleepwear, may enhance comfort.

Aerobic exercise, relaxation techniques, meditation, massage, and yoga may help relieve depression, irritability, and fatigue, as well as reduce hot flashes.

Benefits and risks: Hormone therapy (estrogen plus a progestin) can relieve many symptoms of menopause and may be appropriate if the benefits seem to outweigh the risks. Whether to take hormone therapy is a difficult decision that must be made by a woman and her doctor based on the woman's individual situation. The decision is complicated because interpreting and applying the information about estrogen's benefits and risks is difficult. Recent evidence suggests that hormone therapy is not appropriate for all women. Recent evidence has also raised questions about the long-term use of hormone therapy. For this reason, taking hormone therapy for more than 5 years is no longer recommended.

Estrogen is the most effective treatment for hot flashes. A progestin taken alone may relieve hot flashes and may help prevent osteoporosis but does not affect vaginal dryness.

Estrogen and a progestin can be taken in several ways. They may be taken as two tablets or a combination tablet. Commonly, estrogen and a progestin are taken every day. This schedule typically causes irregular vaginal bleeding for the first year or more of therapy. Alternatively, a cyclic monthly schedule may be followed: Estrogen is taken daily, and a progestin is taken for 12 to 14 days each month. With this schedule, most women have monthly vaginal bleeding.

Other forms include progestin injections, an estrogen skin patch (transdermal estrogen), a combination estrogen-progestin patch, and estrogen creams.

Dosage forms: An estrogen cream may be applied to the vagina, or a ring may be inserted into the vagina (similar to a diaphragm). Or an estrogen tablet may be inserted into the vagina. Applied in these ways, estrogen may help prevent thinning and drying of the vaginal lining. Such treatment helps prevent intercourse from being painful. Some of the estrogen cream is absorbed into the bloodstream, particularly as the vaginal lining becomes healthier. Theoretically, the cream form of estrogen can increase the risk of endometrial cancer. Therefore, if women use this form, they should also take a progestin. The vaginal tablet and ring forms (which do not enter the bloodstream in substantial amounts) may be suggested for women who have breast cancer or a high risk of developing it.

Clonidine, which is used to treat high blood pressure, can reduce the intensity of hot flashes. An antidepressant, such as paroxetine, sertraline, or venlafaxine, may relieve hot flashes.

Alternative Medicine Some women take medicinal herbs and other supplements to relieve hot flashes, irritability, mood changes, and memory loss. Examples are black cohosh, DHEA (dehydroepiandrosterone), dong quai, evening primrose, ginseng, and St. John's wort. However, such remedies are not regulated. That is, they have not been shown to be safe or effective for this use, and what their ingredients are and how much of each ingredient a product contains are not standardized (see Medicinal Herbs and Nutraceuticals: Safety and Effectiveness). Furthermore, some supplements can interact with other drugs and can worsen some disorders. Women who are considering taking such supplements are advised to discuss them with a doctor.

Appendix #2

Query #2 – Osteoporosis

How can I tell if I have osteoporosis? What, specifically, can I do to prevent it?

Merck Manual Home Edition (<http://www.merck.com/mmhe/index.html>)
<http://www.merck.com/mmhe/sec05/ch060/ch060a.html#sec05-ch060-ch060a-74>

Symptoms

At first, osteoporosis produces no symptoms because bone density loss occurs very gradually. Some people never develop symptoms. Eventually, however, bone density may decrease enough for bones to collapse or fracture, producing severe sudden pain or gradually developing aching bone pain and deformities. In long bones, such as the bones of the arms and legs, the fracture usually occurs at the ends of the bones rather than in the middle. In the bones of the spinal column (vertebrae), the fracture usually occurs in the middle to lower back; this type of bone is particularly at risk for fracture due to osteoporosis.

Vertebral crush fractures (fractures of spinal vertebrae) may occur in people who have any type of osteoporosis; these fractures are called osteoporotic fractures. The weakened vertebrae may collapse spontaneously or after a slight injury. Chronic back pain may occur because of these fractures. Usually, pain starts suddenly, stays in a particular area of the back, and worsens when a person stands or walks. The area may be tender. Usually the pain and tenderness go away gradually after a few weeks or months. If several vertebrae break, an abnormal curvature of the spine (a "dowager's hump") may develop, causing muscle strain and soreness as well as deformity.

Bones in other parts of the body may fracture, often because of a minor strain or fall. One of the most serious fractures is a hip fracture, a major cause of disability and loss of independence in older people (see [Fractures: Hip](#)). Wrist fractures, called Colles' fractures (see [Fractures: Arm](#)), occur commonly, especially in people with postmenopausal osteoporosis. In addition, fractures tend to heal slowly in people who have osteoporosis.

Prevention

Prevention is generally more successful than treatment—it is easier to prevent loss of bone density than to restore density once it has been lost. Prevention involves maintaining or increasing bone density by consuming adequate amounts of calcium and vitamin D, engaging in weight-bearing exercise, and, for some people, taking certain drugs.

Consuming an adequate amount of calcium and vitamin D is effective, especially before maximum bone density is reached (around age 30) but also after this time. About 1500 milligrams of calcium and 400 to 800 units of vitamin D daily are recommended. Drinking two 8-ounce glasses of vitamin D-fortified milk, eating a balanced diet, and taking a vitamin D supplement are important, but many women may also need to take a calcium supplement. Many calcium preparations are available; some include supplemental vitamin D.

Weight-bearing exercise, such as walking and stair-climbing, increases bone density. Exercises that do not involve weight bearing, such as swimming, do not increase bone density. Exercise is also important to improve balance, which can help to prevent a fracture that may occur from falling. Curiously, in premenopausal women, high degrees of exercise, such as occurs in athletes, can actually cause a small reduction in bone density because such exercise suppresses the production of estrogen by the ovaries.

Drugs called bisphosphonates, such as alendronate or risedronate, may be used alone as preventive therapy or, in women, combined with estrogen replacement therapy.

Estrogen replacement therapy helps maintain bone density in women. This therapy is most effective when started within 4 to 6 years after menopause, but starting it later can still slow bone loss and reduce the risk of fractures. Decisions about using estrogen replacement therapy after menopause are complex (see [Menopause: Hormone Therapy](#)), because the treatment may have side effects and risks, including an increased risk of uterine cancer and a slightly increased risk of breast cancer. Taking progesterone with the estrogen reduces the risk of uterine cancer but not of breast cancer. Raloxifene is an estrogen-like drug that may be less effective than estrogen in preventing bone loss, but it does not have estrogen's typical side effects on the breast and uterus. Raloxifene is used in people who cannot or prefer not to take estrogen.

Appendix #3

Query #3: Prostate Cancer

My husband has just been diagnosed with prostate cancer. What will he be going through, and what can I expect to happen?

Merck Manual Home Edition (<http://www.merck.com/mmhe/index.html>)
http://www.merck.com/mmhe/sec21/ch239/ch239c.html#tb239_1

Section: Men's Health Issues
Subject: Prostate Disorders

Treatment

Choosing among treatment options can be complicated and often depends on the man's lifestyle preferences. For many men, doctors are uncertain about which treatments are most effective and how likely it is that a particular treatment will prolong a man's life. Some treatments can impair quality of life. For example, major surgery, radiation therapy, and hormonal therapy often cause incontinence and erectile dysfunction (impotence). When choosing among treatment options, men need to weigh the advantages and disadvantages. For these reasons, a man's preferences are a bigger consideration in choosing treatment for prostate cancer than they might be in choosing treatment for many other diseases.

Treatment for prostate cancer usually involves one of three strategies: watchful waiting, curative treatment, and palliative therapy.

Watchful waiting foregoes all treatment until symptoms develop, if they develop at all. This strategy is best for men whose cancers are unlikely to spread or cause symptoms. For example, most cancers that are confined to a small area within the prostate and have low Gleason scores grow very slowly. These cancers usually do not spread for many years. Older men are far more likely to die before such cancers kill them or cause symptoms. Watchful waiting avoids the incontinence and erectile dysfunction associated with many treatments. During watchful waiting, symptoms can be treated if necessary. Periodic testing may also be done to see if the cancer is growing rapidly or spreading. The man may later decide to pursue a cure for the cancer if testing shows growth or spread.

Curative treatment is a common strategy for men with cancers confined to the prostate that are likely to cause troublesome symptoms or death. Such cancers include any that are growing rapidly. Curative (also called definitive) therapy may also help men with small, slowly growing cancers if the man expects to otherwise live many years. Symptoms from such cancers are unlikely to develop in less than a decade and may not do so for 15 or more years. Curative therapy can also benefit men with cancers that have spread outside the prostate and thus are likely to cause symptoms in a relatively short period. However, curative therapy is likely to be successful only with cancers that are still confined to the area near the prostate. Curative therapy can prolong life and reduce or eliminate severe symptoms resulting from some cancers. However, side effects of curative therapy, most significantly permanent erectile dysfunction and incontinence, can impair quality of life.

Palliative therapy aims at treating the symptoms rather than the cancer itself. This strategy is best suited to men with widespread prostate cancer that is not curable. The growth or spread of such cancers can usually be slowed or temporarily reversed, relieving symptoms. Since these treatments cannot cure the cancer, symptoms eventually worsen. Death from the disease eventually follows.

Three forms of treatment can be used to treat prostate cancer: surgery, radiation therapy, and hormonal therapy. Chemotherapy is not usually used.

Surgery Surgically removing the prostate (prostatectomy) is useful for cancer that is confined to the prostate. Prostatectomy is less effective in curing fast-growing cancers because they are more likely to have spread at the time of diagnosis. Prostatectomy requires general anesthesia, an overnight hospital stay, and a surgical incision, but treatment is accomplished with one procedure. Prostatectomy may lead to permanent erectile dysfunction and urinary incontinence.

There are three forms of prostatectomy: radical prostatectomy, nerve-sparing radical prostatectomy, and laparoscopic radical prostatectomy.

In radical prostatectomy, the entire prostate, the seminal vesicles, and part of the vas deferens are removed. This is the surgery most likely to cure prostate cancer. However, the procedure causes complete incontinence in about 3% of men and partial or stress incontinence in up to 20%. Temporary incontinence develops in most men and may last for several months. Incontinence is less likely in younger men. Erectile dysfunction commonly develops after radical prostatectomy. More than 90% of men with cancer confined to the prostate live at least 10 years after radical prostatectomy. Younger men who can otherwise expect to live at least 10 to 15 more years are most likely to benefit from radical prostatectomy.

Sometimes, depending on the estimated size and location of the cancer, surgery can be performed in such a way that some of the nerves needed to achieve erection are spared—this procedure is called nerve-sparing radical prostatectomy. This procedure cannot be used to treat cancer that has invaded the nerves and blood vessels of the prostate. Nerve-sparing radical prostatectomy is less likely than non-nerve-sparing radical prostatectomy to cause erectile dysfunction.

Another form of prostatectomy is laparoscopic radical prostatectomy. The advantages of this procedure are that it requires a smaller incision and produces less postoperative pain. Disadvantages include increased expense and longer operative time. Because this procedure is technically demanding, it is offered only at certain centers.

Radiation Therapy The goal of radiation therapy is to kill the cancer and preserve healthy tissue. Radiation may cure cancers that are confined to the prostate, as well as cancers that have invaded tissues around the prostate (but not cancer that has spread to distant organs). Radiation therapy can also relieve the pain resulting from the spread of prostate cancer to bone but cannot cure the cancer itself.

For many stages of prostate cancer, 10-year survival rates with radiation therapy are nearly as high as those achieved with surgery: more than 90% of men with cancer confined to the prostate live at least 10 years after undergoing

radiation therapy. Whereas surgery is accomplished in one procedure, radiation therapy usually requires many separate treatment sessions over the course of several weeks.

During traditional radiation therapy, a machine sends beams of radiation to the prostate and surrounding tissues (traditional external beam radiation). A CT scanner is used to identify the prostate and surrounding tissues that are affected by the cancer. Treatments are usually given 5 days per week for 5 to 7 weeks. Although erectile dysfunction can occur in 30% of men, it is less likely to develop after radiation therapy than after prostatectomy. Traditional external beam radiation therapy causes incontinence in fewer than 5% of men. Urethral strictures—scars that narrow the urethra and impede the flow of urine—develop in about 7% of men. Other troublesome but usually temporary side effects of traditional external radiation therapy include burning during urination, having to urinate frequently, blood in the urine, diarrhea that is sometimes bloody, irritation of the rectum and diarrhea (radiation proctitis), and sudden urges to defecate.

With recent technical advances, doctors can more precisely focus the radiation beam on the cancer (a procedure called three-dimensional conformal radiotherapy). Cure rates for traditional external beam radiation and three-dimensional conformal radiotherapy have not yet been compared. However, conformal radiotherapy causes fewer temporary side effects.

Radiation can also be delivered by inserting radioactive implants into the prostate (brachytherapy). The implants are placed using images obtained from ultrasound or CT scans. Brachytherapy offers many advantages: it can deliver high doses of radiation to the prostate while sparing healthy surrounding tissues and producing fewer side effects. Brachytherapy can be performed in a few hours, does not require repeated treatment sessions, and uses only spinal anesthesia. However, brachytherapy may cause urethral strictures in up to 20% of men. Cure rates for brachytherapy have not yet been compared to those from other treatments. Combined treatment with brachytherapy and external beam radiation is sometimes recommended.

Prostate cancer can be resistant to radiation therapy or can recur after treatment.

Hormonal Therapy Because most prostate cancers require testosterone^{SOME TRADE NAMES DELATESTRYL DEPOTESTOSTERONE} to grow or spread, treatments that block the effects of this hormone (hormonal therapy) can slow progression of the tumors. Hormonal therapy is commonly used to delay the spread of the cancer or to treat widespread (metastatic) prostate cancer and is sometimes combined with other treatments. Growth and spread of metastatic prostate cancer can be slowed or temporarily reversed with hormonal therapy. Hormonal therapy can prolong life as well as improve symptoms. Eventually, however, hormonal therapy becomes ineffective, and the disease progresses.

Drugs used to treat prostate cancer in the United States include leuprolide^{SOME TRADE NAMES LUPRON} and goserelin^{SOME TRADE NAMES ZOLADEX}, which prevent the pituitary gland from stimulating the testes to make testosterone^{SOME TRADE NAMES DELATESTRYL DEPOTESTOSTERONE}. These drugs are administered by injection in a doctor's office every 1, 3, 4, or 12 months, usually for the rest of the man's life.

Drugs that block testosterone^{SOME TRADE NAMES DELATESTRYL DEPOTESTOSTERONE}'s effects (such as flutamide^{SOME TRADE NAMES EULEXIN}, bicalutamide^{SOME TRADE NAMES CASODEX}, and nilutamide^{SOME}

(**TRADE NAMES NILANDRON**) may also be used. These drugs are taken daily by mouth. However, drugs that block testosterone (**SOME TRADE NAMES DELATESTRYL DEPOTESTOSTERONE**) produce changes associated with low testosterone (**SOME TRADE NAMES DELATESTRYL DEPOTESTOSTERONE**) levels, such as hot flashes, osteoporosis, loss of energy, reduced muscle mass, fluid weight gain, reduced libido, reduced body hair, and often erectile dysfunction and breast enlargement (gynecomastia).

The oldest form of hormonal therapy involves the removal of both testes (bilateral orchiectomy). The effects of bilateral orchiectomy on testosterone (**SOME TRADE NAMES DELATESTRYL DEPOTESTOSTERONE**) level are equivalent to those produced by leuprolide (**SOME TRADE NAMES LUPRON**) and goserelin (**SOME TRADE NAMES ZOLADEX**). Bilateral orchiectomy greatly slows the growth of the prostate cancer but produces the side effects of low testosterone (**SOME TRADE NAMES DELATESTRYL DEPOTESTOSTERONE**) levels. The physical and psychologic effects of bilateral orchiectomy make the procedure difficult for some men to accept.

Hormonal therapy usually becomes ineffective within 3 to 5 years in men with widespread prostate cancer. When cancer eventually progresses despite hormonal therapy, most men die within 1 or 2 years. When hormonal therapy fails (hormone resistance), alternative hormone drugs or chemotherapy may be tried.

After all forms of treatment, PSA levels are measured at regular intervals depending on the risk for recurrence and the time from treatment completion (usually every 3 to 4 months for the first year, every 6 months for the next year, and then every year for the rest of the man's life). Increases in the PSA levels may indicate that the cancer has recurred.

Common Methods and Strategies for Treating Prostate Cancer		
Characteristics of the Cancer	Treatment Strategy	Method of Treatment
Small, slow-growing cancer, confined to prostate; man expected to live many years	Definitive therapy	Surgery or radiation therapy
Small, slow-growing cancer, confined to prostate; man not expected to live many years	Watchful waiting	No treatment
Large or fast-growing cancer, confined to prostate	Definitive therapy	Surgery or radiation therapy
Cancer spread to areas around the prostate, but not to distant areas	Definitive therapy	Radiation therapy
Widespread cancer	Palliative therapy	Hormonal therapy

Appendix #4

Query #4: Ear Infections and Tubes

My child has had several painful ear infections and I'm worried whether she might suffer permanent hearing loss. I've seen other children with tubes in their ears. Should my child have these tubes?

Merck Manual Home Edition (<http://www.merck.com/mmhe/index.html>)
http://www.merck.com/mmhe/sec23/ch276/ch276b.html#fg276_1

Section: Children's Health Issues
Subject: Ear, Nose, and Throat Disorders

Middle ear infections are extremely common between the ages of 3 months and 3 years and often accompany the common cold. Young children are susceptible to middle ear infections for several reasons. The eustachian tube, which balances pressure within the ear, connects the middle ear with the nasal passages (see [The Eustachian Tube: Keeping Air Pressure Equal](#) ). In older children and adults, the tube is more vertical, wider, and fairly rigid, and secretions that pass into it from the nasal passages drain easily. But in younger children, the eustachian tube is more horizontal, narrower, and less rigid. The tube is more likely to become obstructed by secretions and to collapse, trapping those secretions in or close to the middle ear and impairing middle ear ventilation. Any viruses or bacteria in the secretions then multiply, causing infection. Viruses and bacteria can move back up the short eustachian tube of infants, causing middle ear infections.

Besides differences in anatomy of the ear, infants at about the age of 6 months become more susceptible to infection because they lose protection from their mother's antibodies, which they received through the placenta before birth. Breastfeeding appears to partially protect children from ear infections because the mother's antibodies are contained in breast milk. Children also become more sociable around this time and may develop viral infections by touching other children and objects and putting their fingers in their mouth and nose; these infections may in turn lead to middle ear infections. Exposure to cigarette smoke further increases the risk for middle ear infections, as does the use of a pacifier, both of which may impair the function of the eustachian tube and affect middle ear ventilation. Attendance at childcare centers increases the risk of exposure to the common cold and hence to otitis media.

Middle ear infections can resolve relatively quickly (acute), or they can recur or persist over a long time (chronic).

ACUTE MIDDLE EAR INFECTION

Acute middle ear infection (also called acute otitis media (see [Middle and Inner Ear Disorders: Otitis Media \(Acute\)](#))) is most often caused by the same viruses that cause the common cold. Acute infection may also be caused by bacteria found in the mouth and nose, such as *Streptococcus pneumoniae*, *Haemophilus influenzae*, and *Moraxella catarrhalis*. An infection initially caused by a virus sometimes leads to a bacterial infection.

Infants with acute middle ear infections have fever, crying or irritability that sometimes cannot be explained, and disturbances in sleep. They may also have a runny nose, cough, vomiting, and diarrhea. Infants and children who

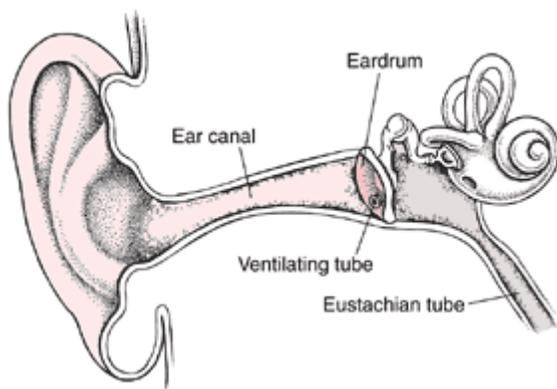
cannot fully communicate may pull at their ears. Older children are usually able to tell parents that their ear hurts or that they cannot hear well.

Commonly, fluid may accumulate behind the eardrum and persist after the acute infection has resolved (serous otitis media). Rarely, acute middle ear infection leads to more serious complications. Rupture of the eardrum can cause drainage of blood or fluid from the ear. Infection of the bone surrounding the ear (mastoiditis) can cause pain; infection of the inner ear (labyrinthitis) can cause dizziness and deafness; and infection of the tissues surrounding the brain (meningitis) or brain abscesses (collections of pus) can cause seizures and other neurologic problems. Recurring infections can promote growth of skinlike tissue through the eardrum (cholesteatoma). Cholesteatoma can damage the bones of the middle ear and cause hearing loss.

Doctors diagnose acute middle ear infections by looking for bulging and redness of the eardrum with an otoscope. They may need to clean wax from the ear first so they can see more clearly. Doctors may use a rubber bulb and tube attached to the otoscope to squeeze air into the ear to see if the eardrum moves. If the eardrum does not move or moves only slightly, then infection may be present.

Acetaminophen or ibuprofen is effective for fever and pain. Doctors used to give antibiotics to all children with acute middle ear infections. However, they now realize that many acute middle ear infections improve without antibiotics. Thus, many doctors use antibiotics (such as amoxicillin with or without clavulanate, or trimethoprim with sulfamethoxazole) only when the child does not improve after a brief period of time or if there are signs that the infection is not getting better.

Ventilating Tubes: Treating Recurring Ear Infections



Ventilating (tympanostomy) tubes are tiny, hollow plastic or metal tubes that are placed in the eardrum through a small slit. These tubes equalize the pressure between the environment and the middle ear. Doctors recommend ventilating tubes for children who have had recurring ear infections (acute otitis media) or chronic fluid collections in their middle ears (serous otitis media).

Placement of ventilating tubes is a common surgical procedure, performed in a hospital or doctor's office. After the procedure, children usually go home within a few hours. The tubes usually fall out on their own after a few months,

although some types stay in for a year or more. Children with ventilating tubes may wash their hair and go swimming, but some doctors recommend that the children not submerge their head completely in water without using earplugs. Drainage of fluid from the ears indicates an infection and the doctor should be notified.

CHRONIC MIDDLE EAR INFECTION

Chronic middle ear infection occurs as a result of repeated acute infection or when recurring infections damage the eardrum or lead to formation of a cholesteatoma, which in turn promotes more infection. Chronic ear infections are more likely among children who are exposed to cigarette smoke, use pacifiers, and attend group day care centers. For children with chronic ear infections, doctors may recommend daily antibiotics for several months. If infection persists or recurs despite the use of antibiotics, or if chronic infections have led to eardrum damage or formation of cholesteatoma, doctors may recommend ventilating (tympanostomy) tubes, eardrum repair, or surgical removal of the cholesteatoma.

Appendix #5

Query #5: Alzheimer's Disease

My mother is increasingly forgetful and I'm worried that she may have Alzheimer Disease. How do I know if she has Alzheimer's and what should I do?

Merck Manual Home Edition (<http://www.merck.com/mmhe/index.html>)
<http://www.merck.com/mmhe/sec06/ch083/ch083c.html#sec06-ch083-ch083c-522>

Symptoms

Dementia resulting from Alzheimer's disease usually begins subtly. People whose disease develops while they are still employed may not perform as well in their jobs. In those who are retired and not very active, the changes may not be as noticeable. The first sign may be forgetting recent events, although sometimes the disease begins with depression, fears, anxiety, decreased emotion, or other personality changes. In the early stages, judgment and abstract thinking may be impaired. Speech patterns may change slightly; the person may use simpler words, use words incorrectly, or be unable to find the appropriate word. An inability to interpret visual cues may make driving a car difficult. People with Alzheimer's disease may be able to function socially but may behave unusually. For example, they may forget the name of a recent visitor, and their emotions may change unpredictably and rapidly. They may get lost on their way to the store.

As Alzheimer's disease progresses, people have trouble remembering events in the past. They may require help with eating, dressing, bathing, or going to the toilet. Wandering, agitation, irritability, hostility, and physical aggression are common. All sense of time and place is lost: People with Alzheimer's disease may even get lost on their way to the bathroom at home. Their increasing confusion puts them at risk of falling. Psychoses, with hallucinations, delusions, and paranoia, develop at some point in about half of people with Alzheimer's disease.

Eventually, people with Alzheimer's disease cannot walk or take care of their personal needs. They may be incontinent and unable to swallow, eat, or speak. These changes put them at risk of undernutrition, pneumonia, and bedsores (pressure sores). Memory is completely lost. Because these people become totally dependent on others, a nursing home may become necessary. Ultimately, coma and death, often due to infections, result.

Progression is unpredictable. The expected survival from the time the disorder is diagnosed ranges from 2 to 10 years, but usually 3 to 5 years. On average, people with Alzheimer's disease who can no longer walk live no more than 6 months.

Diagnosis

Doctors suspect Alzheimer's disease as the most likely cause of dementia in older people whose memory gradually deteriorates. Although a diagnosis based on examination of the person can be correct most of the time, the diagnosis of Alzheimer's disease is proved only by microscopic examination of brain tissue obtained during an autopsy. When brain tissue is examined, the characteristic loss of nerve cells, neurofibrillary tangles, and senile plaques containing amyloid can be seen throughout the brain but particularly in the area of the temporal lobe that is involved in the formation of new memories. Analysis of spinal fluid and positron emission tomography (PET) (see Diagnosis of

Brain, Spinal Cord, and Nerve Disorders: Positron Emission Tomography) have been suggested as ways to diagnose Alzheimer's disease during life, but these procedures are not yet reliable in predicting who will develop Alzheimer's disease or in identifying people who already have it.

Treatment

General measures for treatment of Alzheimer's disease are the same as for all dementias (see Delirium and Dementia: Treatment).

The use of certain drugs (such as nonsteroidal anti-inflammatory drugs [NSAIDs]) to prevent and slow the progression of Alzheimer's disease is under study. Estrogen and vitamin E may help prevent and slow progression of the disease, although study results are inconsistent. Before any of these substances are taken, their risks and benefits should be discussed with a doctor.

Donepezil SOME TRADE NAMES ARICEPT, rivastigmine SOME TRADE NAMES EXELON, tacrine SOME TRADE NAMES CONEX, and galantamine SOME TRADE NAMES REMINYL increase the levels of the chemical messenger (neurotransmitter) acetylcholine, which may be low in many forms of dementia. These drugs may improve cognitive function temporarily, but they do not slow the progression of the disease. About half of the people who have Alzheimer's disease benefit from these drugs. For these people, the drugs effectively turn the clock back 6 to 9 months. These drugs are most effective in people with mild to moderate disease. Because the drugs are expensive and may have side effects, they should not be continued in people who do not benefit from them. The most common side effects include nausea, vomiting, weight loss, and abdominal pain or cramps. Side effects are usually mild and relatively uncommon with donepezil SOME TRADE NAMES ARICEPT and galantamine SOME TRADE NAMES REMINYL.

An extract of ginkgo biloba (called EGb) has been claimed to have effects similar to those of the drugs described above (see Medicinal Herbs and Nutraceuticals: Ginkgo). However, further study of this medicinal herb is needed.

Appendix #6

Query #1: Menopause

Resources: 4, 10, 18

Resource #4: MedBroadcast

Powered by MediResource. Clicked on "M" under "Browse alphabetically" – then on "Menopause"

Treatment and Prevention

Hormone therapy (HT) uses the hormones estrogen and progesterin, alone or together, to manage the symptoms of menopause.

Estrogen can be taken as a pill, applied as a skin patch, inserted as a vaginal ring, or applied as a vaginal cream. All forms help relieve the symptoms of menopause. One of the effects of estrogen is to help prevent the vaginal walls from thinning and becoming dry and susceptible to infection or to pain during intercourse. Since estrogen has side effects and long-term risks, it's important for a woman and her doctor to weigh the benefits and the risks of taking estrogen.

In a natural menstrual cycle, a woman's body produces progesterone just before her menstrual period. Women who are past menopause and take estrogen increase their risk of developing endometrial cancer (a cancer of the lining of the uterus) from 1 in 1,000 to 4 in 1,000. If progesterone is taken along with the estrogen, the risk of developing endometrial cancer is almost eliminated. If a woman notices abnormal bleeding from the vagina, she should tell her doctor. The doctor may take a biopsy, which is a sample of tissue, from the wall of the uterus to check the endometrial lining.

The terms "natural" and "synthetic" are often used to describe the different types of estrogens and progestins. These terms can be misleading because they can be used to mean different things. Sometimes the term "natural" is used to describe the chemical structure of the hormone (exactly the same as the hormones normally produced by the human body), but other times it's used to describe the source of the active ingredient in the medication (e.g., plants or animals). What's most important is not whether the hormone is natural or synthetic, but whether you're receiving the medication, dose, and dosage form that are most appropriate for you.

Hormone therapy can be taken daily or in cycles. With cyclic therapy, hormones are taken on certain days of the month and women will have bleeding, similar to a light period, every month. With continuous or daily therapy, hormones are taken every day. There is no monthly bleeding, but women may have spotting (small amounts of irregular bleeding) during the first three to six months of continuous therapy. Talk to your doctor about which method would be best for you.

Women who have taken estrogen for more than five years may have a greater risk of developing breast cancer. An individual risk-benefit assessment and regular monitoring are required. In general, estrogen should not be taken if a woman has, or has ever had, breast cancer, advanced endometrial cancer, or abnormal vaginal bleeding.

For women who cannot take hormones, or those who prefer alternatives, there are other treatment options for menopause symptoms, including clonidine, certain antidepressants, and herbal remedies, such as black cohosh. If you're thinking of starting an herbal remedy, speak to your doctor or pharmacist first.

To prevent the bone loss that comes with menopause, women should reduce their alcohol consumption and cigarette use, and make sure to include calcium-rich foods, such as cheese, milk, and other dairy products, in their diets. Exercise and resistance training, also called weight training or strength training, helps prevent osteoporosis and control weight.

Resource #10: Nova Scotia Health Network

Searched for "hot flashes" – all results are "sponsored links." Top three results:

Site #1 - Menopause Hot Flashes. Fast relief from hot flashes, mood swings & more. Get free welcome kit (www.ChangesForWomen.com).

- commercial site
- selling supplements

Site #2 - Menopause Hot Flashes. Info on the symptoms of menopause & possible treatments – menopause (www.MenopauseHelp.com).

- all results are "sponsored results"
- another portal!
- didn't click on any (digging too deep) but all looked to be commercial sites

Site #3 - Menopause Symptoms. The spot to find it! It is all here (<http://Emenopausesymptoms.com/>).

- all results are "sponsored results"
- another portal!
- didn't click on any – all commercial?

Resource #18: Ask.com

Entered hot flashes into search box. 1,196,000 results. Were three sponsored results. Top three results discussed below.

Site #1 - Hot Flashes – Causes Other Than Menopause (www.wdxcyber.com/nmood12.htm).

- webpage written by Frederick R. Jelovsek MD
- not relevant since for "causes other than menopause"

Site #2 - Hotflash! – FAQ08 – What are "hotflashes" and what can I do about them (www.families-first.com/hotflash/faq/faq08.htm).

Not sure who author is. Are many advertisements on the page.

There are a number of things you can do to reduce or prevent hot flashes from occurring.

- Avoiding spicy, hot foods, caffeinated beverages and hot drinks can cut down on the number of flashes.
- Exercise, avoiding overheated rooms, and reducing stress reduce the number and intensity of hot flashes.
- A good stress reducer is meditation and breathing exercises. Deep breathing during hot flashes helps women feel better and quiets the heat.
- It's a good idea to keep the air conditioner going in the summer and keep the heat low in the winter. Your family may complain a bit but when you explain to them how important this is for you they will understand.
- Wearing cotton bedwear helps when sleeping. During the day wearing your clothes in layers is a good idea. You can take off what you need to at the hint of a flash.
- Drinking plenty of cold water with ice also can combat the flashes. You can leave a glass of ice water to sip on your bedtable at night for a quick heat relief.

Site #3 - Menopause symptoms and solutions. Is from Oprah website. (www.oprah.com/health/lifestages.health_life_chart.jhtml).

Menopause Symptoms and Solutions

Women going through perimenopause and menopause may experience many uncomfortable symptoms. Use this chart to find solutions to help ease your discomfort. Many different treatments are effective, so choose the ones that appeal most to you. Remember, it's very important to check with your doctor before trying any of these remedies!

Hot flashes	<ul style="list-style-type: none">● <u>Estrogen replacement</u>● <u>2% bioidentical progesterone cream</u>● Meditation and relaxation● Dietary improvements, like eliminating white rice and foods made from white flour from your diet, as well as soda, alcohol and sweets● Add 45–160 mg of soy isoflavones to your daily diet.● Herbal therapies such as Remifemin or Women's Menocaps, reliable brands found in natural food stores● Acupuncture
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Appendix #7

Query #2: Osteoporosis

Resources: 1, 6, 8, 12, 15

Resource #1: HealthyOntario.com

Entered "osteoporosis" into search box; were 10 results. Clicked on "Osteoporosis;" one result: "A Calcium-Rich Diet Can Prevent A Bad Break." Clicking on the link took me to a blank page. Clicked on "Another Reason To Eat Your Veggies;" found:

Lately, vitamin K has begun to come out from under the shadow of vitamins A, B, C and D as scientists believe it may also play a variety of other important roles, including strengthening of our bones. Vitamin K deficiency is linked to osteoporosis because low levels have been found in those with the condition.

Osteoporosis is a disease characterized by low bone mass and deterioration of bone tissue. This leads to increased bone fragility and risk of fracture, particularly of the hip, spine and wrist. Almost one and a half million Canadians suffer from osteoporosis. Without effective action on osteoporosis prevention and treatment strategies, the Osteoporosis Society of Canada estimates that by 2018 we will be spending at least \$32.5 billion annually treating osteoporotic fractures. As the population ages, these costs will likely rise. The human cost is also extremely high. Osteoporosis can result in disfigurement, lowered self-esteem, reduction or loss of mobility, and decreased independence. The statistics related to hip fractures are particularly disturbing. There were approximately 25,000 hip fractures in Canada in 1993. Seventy percent of hip fractures are osteoporosis-related. Hip fractures result in death in up to 20 percent of cases, and disability in 50 percent of those who survive.

- o Clicked on the "osteoporosis" link in this article – took me to "Conditions"/Osteoporosis page – found:

Symptoms

A bone mineral density test is the only way to know for sure that you have osteoporosis before you actually break a bone. Osteoporosis is often called a "silent thief" because bone loss is similar to being burglarized in the night. By the time you discover something is missing, there's little you can do about the loss. People may not know that they have osteoporosis until their bones become so weak that a sudden strain, bump or fall causes a fracture or a vertebra to collapse. Collapsed vertebrae may initially be felt or seen in the form of severe back pain, loss of height, or stooped posture.

Prevention

By about age 20, the average woman has acquired 98 percent of her skeletal mass. Building strong bones during childhood and adolescence can be the best defense against developing osteoporosis later. You can attain the highest peak bone mass possible and keep your bones strong throughout life by developing a lifestyle that includes proper nutrition and a reasonable amount of physical activity.

Nutrition - our bones need calcium to stay strong. Adults over the age of 50, for example, need 1,500 mg of calcium daily to help preserve bone mass and reduce the risk of fracture. Are you getting enough calcium? To find out, try our calcium calculator. Ensure that you are eating foods that are rich in calcium such as

cheese, yogurt, salmon, tofu (preserved with calcium citrate) and broccoli. Milk is a particularly good source of calcium. Two glasses of milk provide about 600 mg. If you cannot get enough calcium through diet, you may need to take calcium supplements.

Vitamin D is necessary for optimal calcium absorption. The easiest and most natural way to get the 400 I.U.s (800 I.U.s for people aged over 50) that adults require daily is through exposure to sunlight (typically 20 minutes a day). Milk and multivitamin pills are two other good sources of Vitamin D.

Physical activity. Daily physical activity is an important part of a bone-healthy lifestyle. Brisk walking, low impact aerobics and dancing are examples of “weight bearing” activities that help keep your bones strong. Also effective are “resistance” exercises such as weight training. With both types of activities, your skeletal system responds to exercise by slowing bone loss and even increasing the bone mass in order to spread the load over a larger amount of bone.

Avoid smoking. Smokers have faster rates of bone loss and a higher risk of fractures than non-smokers. Women smokers also tend to enter menopause at a slightly younger age than non-smokers. This causes the period of rapid bone loss to occur at an earlier age.

Clicked on “Women” – found “Osteoporosis” under “Hot Topics” – took me to conditions page again

Could click on “Conditions”, then “O”, then “Osteoporosis”

Resource #6: UK NHS

Entered “osteoporosis” in Search NHS Direct search box – 55 results – clicked on “Osteoporosis – Introduction” – then on “Diagnosis,” then on “Prevention.”

Diagnosis

Osteoporosis is often undiagnosed until the weakening of the bones has led to a broken bone. An X-ray cannot reliably measure bone density but is useful to identify spinal fractures.

A bone density scan, called a dual energy X-ray absorptiometry (DEXA) scan, is used to measure the density of bones and compare this to a normal range. This test measures the strength of bones and the risk of fracture.

Prevention

Your genes (the characteristics you inherit from your parents) determine the potential height and strength of your skeleton. However, lifestyle factors, such as diet and exercise, can influence how healthy your bones are and the rate at which they repair themselves. Following a healthy lifestyle throughout life is the best way to delay the onset of osteoporosis, and slow the rate at which your bones become brittle. You can do this by:

Taking regular exercise. Try to do 30 minutes of exercise three times a week. This could be walking, cycling or dancing – whatever you enjoy.

Taking plenty of calcium – at least 1,500 mg per day.

Not smoking- cigarette smoking is associated with increased risk of osteoporosis.

Drinking in moderation. Limit your alcohol intake to a maximum of 21 units per week for men and 14 units for women.

Older people with brittle bones can take steps to reduce the risk of fracturing or breaking a bone. It is a good idea to check your home for hazards that you may trip over, such as trailing wires, and to make sure you have regular sight and hearing tests. Some older people wear special protectors over the hip to cushion any fall.

Resource #8: Canada Health Portal

Entered osteoporosis into search box. There were 10 matches. Top three:

Site #1 - Conditions and Diseases/Bones, Joints and Muscles/Osteoporosis- Health Care Information and resources on Conditions and Diseases/Bones, Joints and Muscles/Osteoporosis - Canada Health Portal 07/20/06 ([http://chp-pcs.gc.ca/CHP/index_e.jsp/pageid/4005/odp/Top/Health/Conditions_and_Diseases/Bones, Joints and Muscles/Osteoporosis](http://chp-pcs.gc.ca/CHP/index_e.jsp/pageid/4005/odp/Top/Health/Conditions_and_Diseases/Bones,_Joints_and_Muscles/Osteoporosis))

- another top three resources

Osteoporosis Society of Canada

The mission of the Osteoporosis Society of Canada is to educate, empower and support individuals and communities in the prevention and treatment of osteoporosis.

Source: *Osteoporosis Society of Canada*

- nothing relevant found here (that would answer query)

Osteoporosis -Info-Sheet for Seniors

In Canada, about one out of four women and one out of eight men over 50 years of age have osteoporosis. This disease can have a devastating effect on people's lives, causing painful fractures, disability or deformity.

Source: *Public Health Agency of Canada*

In Canada, about one out of four women and one out of eight men over 50 years of age have osteoporosis.

This disease can have a devastating effect on people's lives, causing painful fractures, disability or deformity. Unfortunately, there's no evident warning sign until a fracture occurs.

What is osteoporosis?

Bone is a living tissue, constantly renewed through a natural process in which new bone replaces old bone. As we age, the process becomes less efficient and we begin to gradually lose bone. In someone with osteoporosis, bone loss occurs more rapidly, causing the bones to become very thin and weak over time.

When bones become severely weakened by osteoporosis, simple movements – such as bending over to pick up a heavy bag of groceries or sneezing forcefully – can lead to fracture. Wrist, spine and hip fractures are the most common fractures associated with osteoporosis.

Hip fractures related to osteoporosis are a serious problem in seniors, resulting in death in up to 20 percent of cases and disability in up to 50 percent of those who survive. Following a hip fracture, many seniors can no longer live independently, and may require nursing home care.

Who is at risk?

Women are especially at risk of osteoporosis because of the important role that the hormone estrogen plays in keeping their bones healthy. At menopause, estrogen levels fall dramatically, and many women experience an accelerated rate of bone loss.

Although men usually have a greater bone mass than women, they are not immune. As they age, they also lose bone mass and should follow the lifestyle changes recommended to prevent or delay osteoporosis.

Even though no single cause for osteoporosis has been identified, certain factors seem to play a role in the development of the disease (see *The risk factors*). If you have some of these risk factors, you should speak to your doctor about getting a bone density test and take preventive action to reduce the risk.

The risk factors

Some risk factors present a higher risk than others. They are indicated by *.

- slender, small bones
- low calcium diet
- low physical activity
- ovaries removed, or menopause before age 45*
- past menopause
- vitamin D deficiency
- cigarette smoking
- too much caffeine or alcohol intake
- family history of osteoporosis*
- excessive use of some medications (e.g. cortisone, prednisone, anticonvulsants)*
- previous fracture*

Prevention

Include calcium in your diet

Individuals over the age of 50 need 1000 to 1500 mg of calcium each day. As you age, your body doesn't absorb calcium as well, so it's very important to have calcium-rich foods in your diet. If you don't eat enough calcium-rich foods, you may require a calcium supplement.

Calcium daily goal: 4 servings

Food	Servings equiv.
Milk (1 cup/250 mL)	1
Milk powder (3 tbs/45 mL)	1/2
Cheese (1.75 oz = 1" x 1" x 3" = 50 g)	
Provolone (1.75 oz.)	1
Gruyere, Emmental (1.75 oz.)	1
Cheddar, Gouda (1.75 oz.)	1
Mozzarella (1.75 oz.)	1
Partly skimmed mozza. (1.75 oz.)	1
Grated parmesan (1 tbs/15 mL)	1/3
Processed cheese (2 slices)	1
Cottage cheese (1 cup/250 mL)	1/2
Yogurt (3/4 cup/175 mL)	1
Instant oatmeal (1 packet)	1/2
Salmon (with bones, 1 can)	1
Sardines (with bones, 12)	1
Baked beans (1 cup/250 mL)	1/2

Red kidney beans (1 cup/250mL)	1/4
Broccoli (1 cup/250 mL)	1/3
Chinese cabbage (1 cup/250 mL)	1/2
Spinach (cooked, 1/2 cup/125 mL)	1/2
Beet greens (1 cup/250 mL)	1/2
Orange (1 average)	1/4
Rhubarb (frozen, raw, 1 cup/250 mL)	1
Dried figs (10)	1
Almonds (1/2 cup/125 mL)	1/2
Sesame seeds (1/2 cup/125 mL)	1/3
Sunflower seeds (1/2 cup/125 mL)	1/4
Tofu (raw, firm, 1/2 cup/125 mL)	1
Hommus (1 cup/250 mL)	1/2
Molasses, blackstrap (1 tbs/15 mL)	1/2

Calcium-rich ideas

- Add a few tablespoons of milk powder to your beef patties, oatmeal, mashed potatoes, creamy soups and other casseroles (2 to 4 tablespoons)
- Add sesame seeds, sunflower seeds, cheese cubes or dried figs to your salads
- Spread blackstrap molasses on your toast or add to baked beans.
- Replace your morning coffee with a *café au lait* or a hot chocolate milk... Enjoy!

Get enough vitamin D

Calcium is not easily absorbed by the body without vitamin D. Sunlight is the main source of natural vitamin D. Most seniors don't get enough of this vitamin, and a daily supplement of 400 to 800 IU may be recommended (especially in Canada where there's little sun intensity during the winter months).

Be active every day

Your bones react to increased activity by getting stronger. Regular weight-bearing activities such as dancing, walking, hiking and tennis are recommended. In addition, exercise that improves balance and coordination (tai chi, swimming and flexibility exercises) can help reduce falls and fractures. Keep experimenting until you find an activity that's right for you!

Avoid smoking

Smokers have faster rates of bone loss and a higher risk of fractures than non-smokers. Women smokers also tend to enter menopause at a slightly younger age than non-smokers. This causes the period of rapid bone loss to occur at an earlier age.

Watch out for falls!

If you've been diagnosed with osteoporosis, now is the time to put your safety and personal needs first. Preventing falls and fractures should be your number one concern.

Here are a few tips:

- Ask a physiotherapist or occupational therapist to help you establish an exercise program adapted to your abilities and goals.
- Wear comfortable shoes that give good support and watch for uneven ground, sidewalks and floors.
- Don't be in too much of a hurry to catch a bus, answer the phone or respond to a doorbell. Haste may create more problems than it's worth.
- Reduce the risk of accidents in your home by making your house safe. The Public Health Agency of Canada publishes a valuable *Safe Living Guide* to help you make simple changes that will help protect you from falls.

Osteoporosis Health Center

Osteoporosis is a silent, bone-depleting disease. More than 1 million Canadians are affected by osteoporosis, according to current estimates. About 1 in 4 women over age 50 will be affected by this disease, as well as 1 in 8 men.

Source: *Women's Health Matters*

- clicked on "Diagnosis"

Currently Osteoporosis is diagnosed in two ways:

1. **The Presence of an Unexplained Fracture**

Individuals who have a non-traumatic fracture by definition have osteoporosis, if other causes of bone pathology (abnormalities) have been excluded. One of the goals of our osteoporosis program is to diagnose bone loss **before** this occurs.

2. **By Measuring Bone Density**

Bone density tests, like DXA, measure the bone mass and are a good predictor of bone fracture risk. The test measures the density of bone and comparing it to the "bone mineral density" (BMD) of healthy, young adults. The denser the bone, the less likely it will fracture. Conversely, the lower the bone density measure, the greater the risk of a non-traumatic fracture.

Early diagnosis is the first step toward timely treatment and care for people who have osteoporosis or are at risk of developing it. Various methods have been used for over 35 years and new technologies continue to be developed.

Two tests that are useful in the diagnosis of osteoporosis are:

- DXA
- QUS

- then clicked on "Prevention"

Women are interested in preventing the onset of osteoporosis. Individuals need to make informed decisions about initiating health promotion activities. Women hold many roles in our society. This poses a challenge to the time available to participate in many health promotion activities.

Try the self-assessment quizzes to explore your personal risk factors for osteoporosis. You can also use the links below to learn how to make healthy changes to your diet and physical activity level. Learn how your lifestyle behaviours can prevent bone loss and reduce the chance of painful fractures.

Your bones are living, growing tissue. They are constantly remodelling themselves. This process occurs in two stages. The first stage is called bone resorption. Cells called osteoclasts become active on the bone surface and dissolve bone tissue, creating a cavity. The second stage is bone

formation. Other cells, called osteoblasts, fill the cavity with new bone. Osteoporosis is a result of an imbalance between bone resorption and bone formation.

Osteoporosis can be treated. And, in most cases, it can be prevented! In childhood, new bone is added faster than old bone is removed so that your bones become larger and denser as you grow. Adolescence is the most important bone building period. As teenagers, after reaching full height, our bones can become more dense. Calcium and physical activity are important to bone health.

Site #2 - Women/Conditions and Diseases/Osteoporosis- Health Care Information and resources on Women/Conditions and Diseases/Osteoporosis - Canada Health Portal 07/20/06 (http://chp.pcs.gc.ca/CHP/index_e.jsp/pageid/4005/odp/Top/Health/Women/Conditions_and_Diseases/Osteoporosis)

- only one resource

Osteoporosis Health Center

Osteoporosis is a silent, bone-depleting disease. More than 1 million Canadians are affected by osteoporosis, according to current estimates. About 1 in 4 women over age 50 will be affected by this disease, as well as 1 in 8 men.

Source: Women's Health Matters

- same as above

Site #3 -Seniors/Age Related Conditions and Diseases/Osteoporosis- Health Care Information and resources on Seniors/Age Related Conditions and Diseases/Osteoporosis - Canada Health Portal 07/20/06 (http://chp.pcs.gc.ca/CHP/index_e.jsp/pageid/4005/odp/Top/Health/Seniors/Age_Related_Conditions_and_Diseases/Osteoporosis)

- another top three

Osteoporosis -Info-Sheet for Seniors

In Canada, about one out of four women and one out of eight men over 50 years of age have osteoporosis. This disease can have a devastating effect on people's lives, causing painful fractures, disability or deformity.

Source: Public Health Agency of Canada

- same as above

Osteoporosis Society of Canada

The mission of the Osteoporosis Society of Canada is to educate, empower and support individuals and communities in the prevention and treatment of osteoporosis.

Source: Osteoporosis Society of Canada

- same as above

Monograph Series on Aging-related Diseases IX. Osteoarthritis

Definition, nature and classification, mortality, morbidity, and risk factors of osteoarthritis, the most common chronic joint condition in the elderly.

Source: Public Health Agency of Canada

- not relevant (osteoarthritis, not osteoporosis)

Resource #12: Yahoo Canada Health

Entered osteoporosis into search box (selected "search this category"). Only two results

Osteoporosis Online

www.osteoporosis.ca

Presented by the Osteoporosis Society of Canada. Provides up-to-date information on the risks, prevention, diagnosis, and treatment of the disease.

- nothing relevant to the query
- found this one from Canada Health Portal search

Bonehealth.ca

www.bonehealth.ca

Offers consumers and caregivers osteoporosis information as it relates to the drug Actonel.

- Proctor and Gamble!

Website Currently Under Construction Please check back soon

We regret to inform you that the Stepping Stones to Better Bones program has come to a close effective June 1st. The newsletters normally distributed with this program are no longer available. If you have any questions regarding osteoporosis, please consult your doctor or pharmacist

Resource #15: Google

Searched for: osteoporosis. One sponsored link: Osteoporosis Breakthrough

www.ezorbonline.com –

Options for refining results: Treatment, Symptoms, Tests/diagnosis, Causes/risk factors, For patients, For health professionals, From medical authorities, Alternative medicine

Top three:

Site #1 - Osteoporosis Online www.osteoporosis.ca

- same as found in Canada Health Portal and Yahoo Canada Health (Osteoporosis Society of Canada)
- nothing relevant re: query

Site #2 - National Osteoporosis Foundation www.nof.org. Clicked on "About Osteoporosis" > then on "Fast Facts".

Symptoms

Osteoporosis is often called a "silent disease" because bone loss occurs without symptoms. People may not know that they have osteoporosis until their bones become so weak that a sudden strain, bump or fall causes a fracture or a vertebra to collapse. Collapsed vertebrae may initially be felt or seen in the form of severe back pain, loss of height, or spinal deformities such as kyphosis or stooped posture.

Risk Factors

Certain people are more likely to develop osteoporosis than others. Factors that increase the likelihood of developing osteoporosis and fractures are called "risk factors." These risk factors include:

- Personal history of fracture after age 50
- Current low bone mass
- History of fracture in a 1° relative
- Being female
- Being thin and/or having a small frame
- Advanced age

- A family history of osteoporosis
- Estrogen deficiency as a result of menopause, especially early or surgically induced
- Abnormal absence of menstrual periods (amenorrhea)
- Anorexia nervosa
- Low lifetime calcium intake
- Vitamin D deficiency
- Use of certain medications (corticosteroids, chemotherapy, anticonvulsants and others)
- Presence of certain chronic medical conditions
- Low testosterone levels in men
- An inactive lifestyle
- Current cigarette smoking
- Excessive use of alcohol
- Being Caucasian or Asian, although African Americans and Hispanic Americans are at significant risk as well

Women can lose up to 20 percent of their bone mass in the five to seven years following menopause, making them more susceptible to osteoporosis.

Detection

Specialized tests called bone mineral density (BMD) tests can measure bone density in various sites of the body. A BMD test can:

- Detect osteoporosis before a fracture occurs
- Predict chances of fracturing in the future
- Determine rate of bone loss and/or monitor the effects of treatment if a DXA BMD test is conducted at intervals of one year or more

Medicare reimburses for BMD testing every two years.

An increase in BMD testing and osteoporosis treatment was associated with a decrease in hip fracture incidence.

Bone density is an important determinant of fracture risk even in nursing home patients.

There has been a five-fold increase in office visits for osteoporosis (from 1.3 to 6.3 million) in the past 10 years.

Prevention

By about age 20, the average woman has acquired 98 percent of her skeletal mass. Building strong bones during childhood and adolescence can be the best defense against developing osteoporosis later. There are five steps, which together can optimize bone health and help prevent osteoporosis. They are:

- A balanced diet rich in calcium and vitamin D
- Weight-bearing and resistance-training exercises
- A healthy lifestyle with no smoking or excessive alcohol intake
- Talking to one's healthcare professional about bone health
- Bone density testing and medication when appropriate

A study of disease management in a rural healthcare population demonstrated that a preventive program was able to reduce hip fractures and save money.

Site #3 - Patient resources: Osteoporosis -
www.docguide.com/news/content.nsf/PatientResAllCateg/Osteoporosis

Doctor's Guide – Personal Edition

Clicked on “Osteoporosis Information” – the Osteoporosis Prevention and Osteoporosis Facts links go to National Osteoporosis Foundation (result #2 in Google search)

Appears to be a portal

Appendix #8

Query #3: Prostate Cancer

Resources: 2, 6, 7, 13, 14, 16, 17, 18

Resource #2: Health Canada – It's Your Health

Clicked on "Diseases and Conditions" (took me to http://www.hc-sc.gc.ca/dc-ma/index_e.html). Then clicked on "Cancer" in sub-menu. Scrolled down to "Types of Cancer" > "Prostate Cancer." Two articles found:

Prostate Cancer – Public Health Agency of Canada

- nothing re: query

Monograph Series on Aging-related Diseases: X. Prostate Cancer

Treatment

A variety of treatment modalities are used to try to control prostate cancer. Radical prostatectomy (preferably a nerve-sparing procedure, which is thought to have lower rates of associated side effects) or radiation therapy has curative intent in men with localized cancers. Hormonal cytoreductive therapy, using anti-androgen products, is sometimes used as an adjunct in these men too. Local radiotherapy (for regional disease) and partial or total androgen blockade (achieved through chemical or surgical castration) constitute the main treatments for advanced disease. Surgery may be used to assist in staging. The usefulness of hormonal treatments, or anti-androgens, may be enhanced by strategies employing intermittent administration. Bone pain may respond specifically to parenteral strontium.

An extensive review of stage-specific treatment approaches is beyond the scope of this Monograph Series. The reader is referred to existing comprehensive reviews.^{20,27} Although there is general agreement on some parameters for initial treatments of men with various stages of the cancer, major areas of uncertainty exist. These include whether surgery, radiation or delayed therapy is best in early stage disease, whether androgen blockade is warranted in minimal metastatic disease and how best to manage advanced disease resistant to anti-androgen therapy. All active treatments carry an associated morbidity—for example, impotence (at least 20-40%) and incontinence (5-25%) are common with both radiation and surgery for early stage disease,²³⁸ and erectile dysfunction is certain when hormonal treatments are used for later stage cancers.

Thus men with prostate cancer face several uncertainties regarding treatment options, all of which carry significant attendant risks of negative health effects.

Resource #6: UK NHS

Entered prostate cancer into search box > 33 hits.

Second hit looked relevant (Cancer of the prostate - Treatment : NHS Direct Online)

<http://www.nhsdirect.nhs.uk/articles/article.aspx?articleId=82§ionId=13292>

Treatment

There are many different treatments for prostate cancer and deciding what is right is not always straight forward, as there is a balance between treatment and side effects. Urologists often discuss individual cases with specialists in treating cancer (oncologists) as there are many issues to consider.

The type of treatment offered depends on the grade and stage of the cancer (how aggressive it is and whether it has spread outside the prostate), the age, and general health. There are four main types of treatment:

'Watchful waiting' - men are seen regularly and have PSA blood tests, but no treatment is given unless their condition deteriorate. Useful for small, slow growing non-aggressive cancers in elderly men where the cancer does not affect their life expectancy.

Prostatectomy - an operation in which the whole prostate is removed. Men are followed up afterwards with regular PSA blood tests to make sure the cancer does not come back. It is only effective in younger men who have aggressive small cancers that have not spread outside of the prostate. It is a major operation with serious side effects. Many men afterwards find it difficult to get or keep an erection, and a minority will be incontinent. Despite this, some men prefer this treatment as the long-term outcome is usually good.

Radiotherapy - x-rays are delivered to the prostate either through the skin from the outside (external beam) or by placing small radioactive seeds directly in the prostate (brachytherapy) to kill cancer cells. It is effective on the same group of men as surgery and often a decision between the two has to be made as the long-term results are similar. The risk of impotence and incontinence after radiotherapy is less than surgery, and radiotherapy has it's own side effects including skin damage and bowel problems.

Hormone Therapy - prostate cancer cells are very sensitive to the male hormone testosterone. By removing this hormone the cancer cells shrink and don't grow, remaining static. Testosterone levels can be lowered by drugs. Men with metastatic prostate cancer i.e. cancer that has spread either locally (around the area of the prostate) or to distant areas (usually the bones) are most suitable for hormone therapy. It is sometimes used before radiotherapy to shrink the cancer down. It can be very effective in controlling the pain associated with cancer which has spread to the bones, and in many men controls their cancer sufficiently for them to live a normal life. Side effects can include lowered libido, possible impotence, hot sweats and breast enlargement, but generally it is tolerated well.

In some circumstances combinations of different treatments are used. It is important for men with prostate cancer to be informed of all the benefits and **risks when deciding what treatment is best for them.**

Resource #7: MedlinePlus

Clicked on "Health Topics" > then "Cancers" > then "Prostate Cancer." This seems to be a portal. Selected two articles:

Prostate Cancer Treatment Options (American Academy of Family Physicians)

<http://familydoctor.org/264.xml>

What are some of the treatment options for prostate cancer?

The treatment options for prostate cancer depend in part on whether the tumor has spread. For tumors that are still inside the prostate, radiation therapy (using x-rays that kill the cancer cells) and a surgery called radical prostatectomy are common treatment options. "Watchful waiting" is also a treatment option. In this approach, no treatment is given until the tumor gets bigger. Watchful waiting may be the best choice for an older man who has a higher risk of dying from something other than his prostate cancer.

Generally, tumors that have grown beyond the edge of the prostate can't be cured with either radiation or surgery. They can be treated with hormones that slow the cancer's growth.

What is radical prostatectomy?

Radical prostatectomy is a surgery to remove the whole prostate gland and the nearby lymph nodes. Most men who have this surgery are under general anesthesia (puts you into a sleep-like state). After the prostate gland is taken out, a catheter (a narrow rubber tube) is put through the penis into the bladder to carry urine out of the body until the area heals.

What are the risks and benefits of radical prostatectomy?

If you're in good health, the short-term risks of this surgery are low. The hospital stay is usually 2 to 3 days, with the catheter left in place for 2 to 3 weeks. You're usually able to go back to work in about 1 month. You shouldn't have severe pain with this surgery. Most men regain bladder control a few weeks to several months after the surgery.

The main advantage of surgery is that it offers the most certain treatment. That is, if all of the cancer is removed during surgery, you are probably cured. Also, the surgery provides your doctor with accurate information about how advanced your cancer is, since the nearby lymph nodes are taken out along with the tumor.

Surgery does have risks and complications. You could lose a lot of blood during this surgery. Before the surgery, you might want to save about 2 units of your own blood in case you need a transfusion. The main risks of this surgery are incontinence (lack of bladder control) and impotence (loss of the ability to get or keep an erection long enough to have sex). Fortunately, only a very low percentage of men have severe incontinence after radical prostatectomy. Up to 35% of men have a little accidental leakage of urine during heavy lifting, coughing or laughing.

The chance of impotence decreases if the surgeon is able to avoid cutting the nerves. This may not be possible if the tumor is large. Your age and degree of sexual function before the surgery are also important factors. If you're under 50 years old when you have this surgery, you're likely to regain sexual function. If you're older than 70, you're more likely to lose sexual function. Remember, even if the nerves are cut, feeling in your penis and orgasm remain normal. Only the ability to get a rigid penis for sexual intercourse is lost. However, there are medicines and devices that can help make the penis rigid.

What is radiation therapy? What are its risks and benefits?

There are 2 types of radiation therapy. In one type, called external beam radiation therapy, radiation is given from a machine like an x-ray machine. In another type, radioactive pellets (called "seeds") are injected into the prostate gland. This is sometimes called seed therapy or brachytherapy (say: "break-ee-ther-uh-pee"). Both types work about the same in curing prostate cancer.

The machine therapy is usually given 5 days a week over 7 weeks, which you might find time-consuming. However, you don't need any anesthesia. The side effects are milder than the side effects that can come with seed therapy. However, seed therapy can be done with just one hospital visit. For seed therapy, you have to have anesthesia for a few minutes, but you should be able to go home right after the treatment. In seed therapy, higher doses of radiation can be put right on the cancer. You may feel more discomfort after this treatment.

About one half of patients become impotent within 2 years of having radiation therapy. Many men feel very tired at the end of the treatment period. About 15% to 30% of men who have radiation therapy have urinary burning, urinary bleeding, frequent urination, rectal bleeding, rectal

discomfort or diarrhea during or shortly after the treatment. Serious complications are rare. However, a degree of uncertainty goes along with radiation treatment. Since the prostate gland and the lymph nodes are not taken out, your doctor can't tell the exact size of the tumor. The cancer could come back many years after radiation treatment.

At 10 years after treatment, cure rates are about the same for radiation therapy and radical prostatectomy. There are no surgical risks for men who have radiation therapy. There's no risk of bleeding. You don't have to stay in the hospital. You'll recover faster. Daily activities can usually go on during the treatment. Incontinence is extremely rare afterward. However, surgery may give you a better chance of cure over the long term.

What are the risks and benefits of watchful waiting?

Many prostate cancers are small and grow slowly. Because many men with a slow-growing tumor have the same life expectancy as men who don't even have prostate cancer, it may not be necessary to treat very small, very slow-growing prostate tumors. Also, some men feel that the side effects of treatment outweigh the benefits. In watchful waiting, you get no treatment, but you see your doctor often. If there's no sign the cancer is growing, you continue to get no treatment. Hormone therapy can be started if the cancer starts to grow.

It can be hard to tell if a small tumor is going to grow slowly or quickly. Your doctor will get clues about the way your tumor will grow by checking your prostate-specific antigen (PSA) level, examining the biopsy tissue and giving you a rectal exam. The choice of watchful waiting is up to you.

What is the purpose of hormone therapy?

The purpose of hormone therapy is to lower the level of the male hormones, called androgens, which are produced mostly in the testicles. This is because androgens, such as testosterone, help the prostate tumor grow. Monthly shots can be given or the testicles can be surgically removed. Once the testosterone is out of your body, the prostate cancer usually shrinks. Hormone treatments are most often used in patients with cancer that has already spread beyond the prostate gland.

While prostate cancer usually responds to 1 or 2 years of hormone therapy, after some time most tumors start to grow again. Once this happens, the treatment goal is to control symptoms. No treatment can cure prostate cancer after hormone therapy stops helping.

What happens after prostate cancer treatment?

You should get PSA (prostate-specific antigen) blood tests every 6 months for 5 years, and then once every year. A rise in PSA levels usually means that the cancer has come back. A digital rectal examination should be done once a year.

Where can I get more information about prostate cancer?

Your family doctor, your oncologist (cancer doctor), the radiotherapist and your urologist can give you information. Your local hospital or cancer center may refer you to a local prostate cancer support group, where you can meet other men who have had this cancer.

Watchful Waiting (Prostate Cancer Foundation)

<http://www.prostatecancerfoundation.org/site/pp.asp?c=itIWK2OSG&b=47304>

Active Surveillance

The concept of active surveillance, or watchful waiting, has increasingly emerged in the past years as a viable option for men who, for one reason or another, have decided not to undergo immediate surgery or radiation therapy. During active surveillance, the cancer is carefully monitored for signs of progression. A PSA blood test and DRE are usually administered every six months along with a yearly biopsy of the prostate. If symptoms develop, or if tests indicate that the cancer is growing, treatment might be warranted.

Active surveillance might be a good choice for men who have very slow growing or very early cancers, or for men who have other serious medical conditions that affect the way they live their lives, especially if these other conditions are likely to shorten their lifespan.

Also, many of the treatment options for prostate cancer can be difficult to endure, and better outcomes are seen in men who are otherwise healthy. If a man is currently battling other disorders or diseases, such as heart disease, long-standing high blood pressure, or poorly controlled diabetes, his doctors might feel that it is in his best interest to hold off on therapy and avoid its potential complications.

Resource #13: Google Health

Clicked on "Conditions and Diseases" > then "Cancer" > then "Genitourinary" (Note: Would consumers know to click on this?) > then "Prostate"

Top three:

Site #1 - MEDLINEplus: Prostate Cancer -

<http://www.nlm.nih.gov/medlineplus/prostatecancer.html>

U.S. National Library of Medicine source which includes links to specific related areas

- already visited

Site #2 - ProstateLine - <http://www.prostateline.com/>

The pharmaceutical firm AstraZeneca presents overview information about the disease

Clicked on "Patients" > then "Living with prostate cancer"

Health issues

Some treatments for prostate cancer may have long-term side-effects (eg long-term tiredness or lack of energy associated with radiotherapy) which require you to make some changes to your lifestyle. You may also need to take medications for a considerable period of time, possibly even for the rest of your life. Your doctor or nurse will discuss with you the particular health issues that concern you and they will be able to provide advice on how to deal with any troubling side-effects.

Importance of follow-up care

Follow-up care after treatment for prostate cancer is very important. Your doctor will examine you regularly to be sure that the disease has not returned or progressed, and will decide what other medical care may be needed. Follow-up examinations may include x-rays, scans and PSA blood tests. It is important that you keep these appointments with your doctor. You may find it useful to maintain a diary of how you have felt since the last visit. This will help your doctor to assess if your current treatment plan is the most appropriate for your condition.

Coping with symptoms

Your doctor or nurse will be able to provide advice on how to deal with symptoms such as difficulty urinating and loss of libido. These symptoms are common in prostate cancer and your health team will be able to suggest coping strategies and to offer you reading material that deals with these topics.

Sexual relationships

It is natural for you and your partner to be concerned about the effect prostate cancer and its treatment might have on your sexual relationship. Many men with prostate cancer can continue to enjoy an active sex

life but some may have problems with impotence caused by their treatment. You may want to talk with your doctor about possible side-effects and whether these are likely to be temporary or permanent. Whatever the outlook, it is usually helpful for you and your partner to talk openly about your concerns and to help one another find ways to be intimate during and after treatment.

Healthy diet and exercise

There is some evidence to suggest that eating a low-fat, high-fibre diet and taking regular exercise can slow prostate cancer cell growth. Your doctor or nurse will be able to provide advice on improving your diet and to suggest the level of exercise suitable for you.

Also clicked on "Patients" > then "Treatment" > lists Watchful waiting, Surgery, Radiotherapy, Hormonal therapy, Chemotherapy, Cryotherapy, Palliative therapy.

Site #3 - Prostate Cancer Control Initiatives -

<http://www.cdc.gov/cancer/prostate/index.htm>

A Centers for Disease Control and Prevention resource that includes specific information, discussion, support and links.

Resource #14: US NIH

Clicked on "Men's Health" > then "Prostate Cancer"

Results from National Cancer Institute, National Institute on Aging, etc.

Very relevant – "What you need to know about prostate cancer" (by National Cancer Institute) – Talks about staging, treatment, CAM, follow-up care

Resource #16: Yahoo

Entered prostate cancer into search box

22,100,000 results

Suggests: "Also try prostate cancer symptoms, prostate cancer treatment. More..."

Four sponsored results – all appear to be commercial

Prostate Cancer – Learn more from MedlinePlus www.nlm.nih.gov/medlineplus/prostatecancer.html

Find the latest news stories, overviews, research and more on Prostate Cancer from MedlinePlus, the National Library of Medicine's consumer health site.

- see above

Prostate Cancer Foundation www.prostatecancerfoundation.org

Private source of funding whose mission is to identify and support prostate cancer research that will rapidly translate into treatments and cures.

Clicked on "Treatment" (there are sub-menu items not listed here)

There is no "one size fits all" treatment for prostate cancer, so each man must learn as much as he can about various treatment options and, in conjunction with his physicians, make his own decision about what is best for him.

For most men, the decision will rest on a combination of clinical and psychological factors. Men diagnosed with localized prostate cancer today will likely live for many years, so any decision that is made now will

likely reverberate for a long time. Careful consideration of the different options is an important first step in deciding on the best treatment course.

Consultation with all three types of prostate cancer specialists—a urologist, a radiation oncologist and a medical oncologist—will offer the most comprehensive assessment of the available treatments and expected outcomes.

Clicked on “Managing Bone Metastases and Pain” (there are sub-menu items not listed here)

Clicked on “Side Effects” (there are sub-menu items not listed here)

Clicked on “Nutrition and Prostate Cancer” (there are sub-menu items not listed here)

Clicked on “Issues to Consider”

Clicked on “Questions to Ask Your Doctor”

The Prostate Cancer Charity www.prostate-cancer.org.uk

Provides support and information services to people affected by prostate cancer and raises funds for and conducts medical research into the condition.

Clicked on “Information” > then “Treatment” (options are listed)

Clicked on “Information” > then, under “Management”, clicked on:

“continence” (http://www.prostate-cancer.org.uk/info/manage_continence.asp)

“pain” (http://www.prostate-cancer.org.uk/info/manage_pain.asp)

“sexuality” (http://www.prostate-cancer.org.uk/info/manage_sex.asp)

Resource #17: MSN

Entered prostate cancer into search box

2,902,033 results

3 sponsored sites

Top three:

Prostate Cancer Home Page - National Cancer Institute

NCI's gateway for information about **prostate cancer**. ... Related Pages: What You Need To Know About **Prostate Cancer**. Information about detection, symptoms ...

www.cancer.gov/cancertopics/types/prostate

- section on treatment

Prostate Cancer Research Institute, Research, Awareness and Education

Non-profit provides access to resources, articles, research and links. Maintained by Drs. Strum and Scholz and located in Los Angeles, California.

www.prostate-cancer.org

- clicked on “Resources” > then “Newly Diagnosed” (in left-hand column)
- articles on “Self-Empowerment” (including e-empowerment!), “Risk Assessment and Algorithms”, “Staging”, “Diagnostic Scanning”

ACS :: Detailed Guide: Prostate Cancer

Detailed Guide: **Prostate Cancer** Get complete information about each of the topics below. Click a document title to read the document. Choose another **cancer** topic

www.cancer.org/docroot/CRI/CRI_2_3x.asp?rnav=cridg&dt=36

- scrolled down and found:

Treating Prostate Cancer

- ▶ [How Is Prostate Cancer Treated?](#)
- ▶ [Expectant Management \(Watchful Waiting\)](#)
- ▶ [Surgery](#)
- ▶ [Radiation Therapy](#)
- ▶ [Cryosurgery](#)
- ▶ [Hormone \(Androgen Deprivation\) Therapy](#)
- ▶ [Chemotherapy](#)
- ▶ [Treatment of Pain and Other Symptoms](#)
- ▶ [Clinical Trials](#)
- ▶ [Complementary and Alternative Therapies](#)
- ▶ [Considering Prostate Cancer Treatment Options](#)
- ▶ [Treatment Options by Stage](#)
- ▶ [More Treatment Information](#)

Talking With Your Doctor

- ▶ [What Should You Ask Your Doctor About Prostate Cancer?](#)
- ▶ [What Will Happen After Treatment for Prostate Cancer?](#)
 - Didn't follow-up on these (to copy here) – but look to be similar to what's been found previously

Resource #18: Ask.com

Entered prostate cancer into search box

3,627,000 results

3 sponsored results

Top three:

Prostate cancer - treatment, symptoms and causes

BUPA health information factsheet - **prostate cancer** is an abnormal growth of cells in the **prostate** gland...

http://hcd2.bupa.co.uk/fact_sheets/Mosby_factsheets/prostate_cancer.html

- commercial site (health insurance, financial protection, etc.)
- section on "Treatment"

Treatment

Your treatment for prostate cancer will depend on a number of factors such as your age and whether the cancer has spread and if so, how far. There are a number of treatments which are described below. Some can have serious side-effects so it is important to discuss them in more detail with your doctor who will advise you which treatment is best for you.

Active monitoring

Sometimes, particularly for slow-growing tumours, no treatment is the best course of action. This is often called active monitoring or watchful waiting. Your condition will be monitored closely with routine check-ups. You can start treatment at any time and will be advised to do so if tests show the cancer is growing.⁵

Surgery

Surgery is a common treatment for prostate cancer. It is most suitable for otherwise healthy men (usually, those under 70) whose cancer has not spread beyond the prostate.⁵

The most common technique is a radical prostatectomy. This is a major operation, which removes the whole of the prostate, seminal vesicles and nearby lymph nodes.²

Radiotherapy

Radiotherapy uses radiation to destroy cancer cells. For more information, please see the separate BUPA factsheet:

Radiotherapy

Newer techniques that are used for treating prostate cancer with radiotherapy include conformal radiotherapy (CRT) or high-resolution intensity modulated radiotherapy (IMRT). Conformal radiotherapy shapes the radiation beams to match the shape of the prostate. This reduces the radiation received by the healthy surrounding cells in nearby organs such as the bladder and rectum. This lowers the side-effects and may allow higher doses to be given which could be more effective. IMRT allows the radiotherapist to vary the dose of radiotherapy given to the tumour and surrounding tissue.⁵

Brachytherapy

Brachytherapy involves implanting radioactive seeds into, or next to, the tumour in your prostate. Radiation can be released slowly over time. The seeds lose their radioactivity over about a year.⁵ Brachytherapy is more effective if the tumour is small and you have early prostate cancer.^{2,6}

Hormone therapy

Hormone therapy blocks the action of male sex hormones that help cancer grow. This can slow the growth and spread of prostate tumours but will not kill the cancer cells.

Medical hormone therapies include goserelin (Zoladex) and bicalutamide (Casodex).⁷

Alternatively, surgical hormone therapy involves removing your testicles, which permanently gets rid of the main source of testosterone. This operation is called an orchidectomy. It is possible for you to keep your scrotum and just have the testes (the organs inside it) removed.

This treatment is less common than it used to be as many men prefer to take drugs to block their testosterone instead.²

New treatments

There are new treatments being developed such as cryotherapy. This is surgery to freeze the prostate with liquid gas and kill cancer cells.⁸

High intensity focused ultrasound (HIFU) is a treatment given using a machine that gives off high frequency sound waves. Some cancer cells die when this is focused directly onto them.^{6,9}

New surgical developments include keyhole surgery (a laparoscopic prostatectomy) where the prostate is removed through smaller incisions.¹⁰

Prostate Cancer Info : education, support, male hormone therapy, PSA ...

Prostate cancer info on **prostate cancer** education, **prostate cancer** support, and **prostate cancer** diagnosis including male hormone therapy,

www.prostateinfo.com/

Clicked on "For Patients" > then "Treatment Methods" – similar to previous findings, many options

Clicked on "For Patients" > then "Support"

Ways to Cope With Your Diagnosis and Treatment

Learning that you have prostate cancer brings up a lot of feelings that you may find hard to deal with. It's only natural to be concerned about your treatment, side effects, the future, and how your illness will affect you and your loved ones. Take advantage of all the help you can find, especially from your health care team. Tell them what you are feeling and what you need.

How am I expected to feel?

There is no one way to react to prostate cancer, and every man is entitled to his own experience. One common worry is about treatments that affect sexual performance, which causes many men to feel a threat to their masculinity. Others find prostate cancer embarrassing to talk about. Whatever you feel, try not to push your feelings away. That can cause even more stress.

What's the best way to cope with my diagnosis?

Become a partner with your health care team (your urologist, radiation oncologist, medical oncologist, nurse, technician, counselor). Ask questions about your condition, the risks, benefits, and side effects of each treatment option, and the impact your choice will have on your life. It's a good idea to write down all your questions and answers so you can refer to the information at any time. Once you have decided on a treatment option, follow your health care team's advice and let them know about any new symptoms or other concerns.

How will prostate cancer affect my relationships?

Talk about your illness with your family and close friends. Some people may shy away at first because they want to help you but don't know how. Being open about what you need can help you maintain relationships that will support you.

How much should I tell my partner?

The honest sharing of thoughts and feelings can create an even greater intimacy. It's important to talk to each other about how certain decisions will affect your life together. For example, if a possible side effect of your treatment is impotence (inability to have an erection), you and your partner may decide to talk about other ways you each can still enjoy sex.

If you need help starting conversations with your partner, you may each want to first write down your feelings and concerns. Or, you may want to talk to a professional counselor specializing in erectile dysfunction. Your health care team can help you find a counselor.

MedlinePlus: Prostate Cancer

Prostate Cancer ... Search MEDLINE/PubMed for recent research articles on **Prostate Cancer**: • **Prostate cancer** • **Prostate cancer** therapy ...

www.nlm.nih.gov/medlineplus/prostatecancer.html

- see above (looked at previously)

Appendix #9

Query #4: Ear Infections and Tubes

Resources: 3, 14, 17

Resource #3 – MediResource

This is the Health and Fitness feature of Sympatico-MSN.

Clicked on "Disease Library. "Clicked on "Agree" under terms and conditions. From alphabet clicked on "E." Clicked on "Ear Infections" (http://mediresource.sympatico.ca/disease_detail.asp?disease_id=99).

Answer:

Otitis Media

Earache · Ear Infection · Middle Ear Infection

The Facts

Otitis media is a middle ear infection that is most common in infants and young children, from three months to three years of age. It has been shown that by the age of one year, more than 60% of children will have had one or more middle ear infections. Although a middle ear infection can occur at any age, it's much less common in older children and adults.

Causes

The middle ear is connected to the throat by a small tube called the eustachian tube. It's protected from the outside by a thin shield called a membrane. Viruses and bacteria that normally live in the throat can sometimes cross into the middle ear - through the eustachian tube - causing an infection.

Winter is high season for ear infections. They often follow a cold. Some factors that increase a child's risk for middle ear infections include:

- crowded living or daycare conditions
- exposure to second-hand smoke
- respiratory illnesses
- close contact with siblings who have colds or ear infections
- having a cleft palate
- allergies that cause congestion on a chronic basis

Barometric trauma is another cause of ear infection. The pressure in the middle ear rises when the airplane you are travelling on descends or when you ascend while scuba diving. If the eustachian tube is not open, the pressure in the middle ear cannot be equalized, and thus, may cause injury and an acute ear infection.

Symptoms and Complications

Middle ear infections can be categorized as acute, serous, or chronic.

Common symptoms of acute otitis media are fever, pain, and irritability. In children, the ear infection often begins after the child has had a cold for several days.

It's more difficult to detect signs of ear infection in young babies. You may notice a change in mood or feeding, and the infant will most likely have a fever. Because ear infections are usually painful, many babies will be irritable.

If fluid builds up in the ear, the infection is called serous otitis media. This occurs when the eustachian tube becomes blocked, and pressure in the middle ear drops. Under these circumstances, the child might experience hearing loss or

impairment in the infected ear. This is usually only temporary. While this is usually no cause for alarm, anyone who experiences hearing loss or impairment should consult their doctor (and expect a follow-up).

Chronic otitis media refers to recurring ear infections. This is often complicated by (or caused by) a hole in the eardrum (perforation) from any one of the following:

- acute infection
- blocked eustachian tube
- heat or chemical burns
- injury from sudden air pressure changes
- injury from an object entering the ear

Chronic ear infections often flare up after a cold, or, if perforated, when water enters the ear during swimming or bathing. Repeated infections can destroy the small bones in the middle ear, leading to long-term hearing loss. More serious complications include spread to nearby organs, appearing as inflammation of the inner ear, facial paralysis, and brain infections.

Making the Diagnosis

Based on a visual examination and description of the symptoms, your doctor can diagnose otitis media. In an infected ear, the eardrum usually appears red and swollen. If pus is draining from the ear, a sample can be sent for lab analysis, to identify which type of bacteria is causing the infection.

When fluid builds up in the middle ear, the doctor can perform a tympanometry. This is a simple hearing test that measures the pressure on both sides of the eardrums.

Treatment and Prevention

Otitis media is often treated with antibiotics. To lower the chances of the infection returning, it's very important to take the antibiotics regularly, even if the symptoms improve quickly. Many of the infections are actually caused by viruses, and some doctors believe that a short period of watchful waiting, rather than antibiotics, is appropriate for children who neither have recurrent infections nor structural differences in their ears.

Cold medications (such as decongestants) may be useful for keeping the eustachian tube from becoming blocked. Antihistamines may help people who have allergies. But neither of these medications will cure the ear infection. Pain relievers can be used to ease the pain of the infection and to lower a child's fever. Holding warm cloths over the sore ear may also provide some relief.

Fluid buildup in the middle ear can be drained. In a procedure called a myringotomy, a tiny tube is inserted into an opening of the eardrum that drains fluid away and allows air to reach the middle ear which equalizes the pressure and often allows drainage down the eustachian tube. The cause of fluid accumulation must also be treated. For instance, if allergic reactions are to blame for blocking the eustachian tube, then antihistamines will be given to relieve allergies.

If the child has a permanent hole in his or her eardrum that's causing chronic otitis media, the eardrum itself can be repaired by a procedure called a tympanoplasty.

It's hard to prevent ear infections since many children, especially those who attend daycare, are susceptible to colds. Careful hand-washing regimens can help reduce the chance of catching colds, so it's important to remind your kids to wash up as often as possible.

Breast-feeding seems to lower the chances of developing ear infections among infants and children by helping to boost their immunity. Another good preventative measure is to keep your home smoke-free as smoking damages the cilia, which are the tiny hairs on the cells that help keep the lining clean. Immunization with the pneumococcal vaccine can lessen the likelihood of getting ear infections caused by certain types of bacteria.

Resource #14 – National Institutes of Health

Did a search for "ear infection." Top three sites were links to other pages. Sites number 2 and 3 had no information about ear infections.

Site #1 – Ear, Nose and Throat (<http://www.nidcd.nih.gov/health/hearing/otitism.asp>)

What is otitis media?

Otitis media is an infection or inflammation of the middle ear. This inflammation often begins when infections that cause sore throats, colds, or other respiratory or breathing problems spread to the middle ear. These can be viral or bacterial infections. Seventy-five percent of children experience at least one episode of otitis media by their third birthday. Almost half of these children will have three or more ear infections during their first 3 years. It is estimated that medical costs and lost wages because of otitis media amount to \$5 billion* a year in the United States. Although otitis media is primarily a disease of infants and young children, it can also affect adults.

*Gates GA. Cost-effectiveness considerations in otitis media treatment. *Otolaryngol Head Neck Sur.* April 1996. 114 (4): 525-530.

How do we hear?

The ear consists of three major parts: the outer ear, the middle ear, and the inner ear. The outer ear includes the pinna--the visible part of the ear--and the ear canal. The outer ear extends to the tympanic membrane or eardrum, which separates the outer ear from the middle ear. The middle ear is an air-filled space that is located behind the eardrum. The middle ear contains three tiny bones, the malleus, incus, and stapes, which transmit sound from the eardrum to the inner ear. The inner ear contains the hearing and balance organs. The cochlea contains the hearing organ which converts sound into electrical signals which are associated with the origin of impulses carried by nerves to the brain where their meanings are appreciated.

Why are more children affected by otitis media than adults?

There are many reasons why children are more likely to suffer from otitis media than adults. First, children have more trouble fighting infections. This is because their immune systems are still developing. Another reason has to do with the child's eustachian tube. The eustachian tube is a small passageway that connects the upper part of the throat to the middle ear. It is shorter and straighter in the child than in the adult. It can contribute to otitis media in several ways.

The eustachian tube is usually closed but opens regularly to ventilate or replenish the air in the middle ear. This tube also equalizes middle ear air pressure in response to air pressure changes in the environment. However, a eustachian tube that is blocked by swelling of its lining or plugged with mucus from a cold or for some other reason cannot open to ventilate the middle ear. The lack of ventilation may allow fluid from the tissue that lines the middle ear to accumulate. If the eustachian tube remains plugged, the fluid cannot drain and begins to collect in the normally air-filled middle ear.

One more factor that makes children more susceptible to otitis media is that adenoids in children are larger than they are in adults. Adenoids are composed largely of cells (lymphocytes) that help fight infections. They are positioned in the back of the upper part of the throat near the eustachian tubes. Enlarged adenoids can, because of their size, interfere with the eustachian tube opening. In addition, adenoids may themselves become infected, and the infection may spread into the eustachian tubes.

Bacteria reach the middle ear through the lining or the passageway of the eustachian tube and can then produce infection, which causes swelling of the lining of the middle ear, blocking of the eustachian tube, and migration of white cells from the bloodstream to help fight the infection. In this process the white cells accumulate, often killing bacteria and dying themselves, leading to the formation of pus, a thick yellowish-white fluid in the middle ear. As the fluid increases, the child may have trouble hearing because the eardrum and middle ear bones are unable to move as freely as they should. As the infection worsens, many children also experience severe ear pain. Too much fluid in the ear can put pressure on the eardrum and eventually tear it.

What are the effects of otitis media?

Otitis media not only causes severe pain but may result in serious complications if it is not treated. An untreated infection can travel from the middle ear to the nearby parts of the head, including the brain. Although the hearing

loss caused by otitis media is usually temporary, untreated otitis media may lead to permanent hearing impairment. Persistent fluid in the middle ear and chronic otitis media can reduce a child's hearing at a time that is critical for speech and language development. Children who have early hearing impairment from frequent ear infections are likely to have speech and language disabilities.

How can someone tell if a child has otitis media?

Otitis media is often difficult to detect because most children affected by this disorder do not yet have sufficient speech and language skills to tell someone what is bothering them. Common signs to look for are

- unusual irritability
- difficulty sleeping
- tugging or pulling at one or both ears
- fever
- fluid draining from the ear
- loss of balance
- unresponsiveness to quiet sounds or other signs of hearing difficulty such as sitting too close to the television or being inattentive

Can anything be done to prevent otitis media?

Specific prevention strategies applicable to all infants and children such as immunization against viral respiratory infections or specifically against the bacteria that cause otitis media are not currently available. Nevertheless, it is known that children who are cared for in group settings, as well as children who live with adults who smoke cigarettes, have more ear infections. Therefore, a child who is prone to otitis media should avoid contact with sick playmates and environmental tobacco smoke. Infants who nurse from a bottle while lying down also appear to develop otitis media more frequently. Children who have been breast-fed often have fewer episodes of otitis media. Research has shown that cold and allergy medications such as antihistamines and decongestants are not helpful in preventing ear infections. The best hope for avoiding ear infections is the development of vaccines against the bacteria that most often cause otitis media. Scientists are currently developing vaccines that show promise in preventing otitis media. Additional clinical research must be completed to ensure their effectiveness and safety.

How does a child's physician diagnose otitis media?

The simplest way to detect an active infection in the middle ear is to look in the child's ear with an otoscope, a light instrument that allows the physician to examine the outer ear and the eardrum. Inflammation of the eardrum indicates an infection. There are several ways that a physician checks for middle ear fluid. The use of a special type of otoscope called a pneumatic otoscope allows the physician to blow a puff of air onto the eardrum to test eardrum movement. (An eardrum with fluid behind it does not move as well as an eardrum with air behind it.)

A useful test of middle ear function is called tympanometry. This test requires insertion of a small soft plug into the opening of the child's ear canal. The plug contains a speaker, a microphone, and a device that is able to change the air pressure in the ear canal, allowing for several measures of the middle ear. The child feels air pressure changes in the ear or hears a few brief tones. While this test provides information on the condition of the middle ear, it does not determine how well the child hears. A physician may suggest a hearing test for a child who has frequent ear infections to determine the extent of hearing loss. The hearing test is usually performed by an audiologist, a person who is specially trained to measure hearing.

How is otitis media treated?

Many physicians recommend the use of an antibiotic (a drug that kills bacteria) when there is an active middle ear infection. If a child is experiencing pain, the physician may also recommend a pain reliever. Following the physician's instructions is very important. Once started, the antibiotic should be taken until it is finished. Most physicians will have the child return for a followup examination to see if the infection has cleared.

Unfortunately, there are many bacteria that can cause otitis media, and some have become resistant to some antibiotics. This happens when antibiotics are given for coughs, colds, flu, or viral infections where antibiotic treatment is not useful. When bacteria become resistant to antibiotics, those treatments are then less effective against

infections. This means that several different antibiotics may have to be tried before an ear infection clears. Antibiotics may also produce unwanted side effects such as nausea, diarrhea, and rashes.**

Once the infection clears, fluid may remain in the middle ear for several months. Middle ear fluid that is not infected often disappears after 3 to 6 weeks. Neither antihistamines nor decongestants are recommended as helpful in the treatment of otitis media at any stage in the disease process. Sometimes physicians will treat the child with an antibiotic to hasten the elimination of the fluid. If the fluid persists for more than 3 months and is associated with a loss of hearing, many physicians suggest the insertion of "tubes" in the affected ears. This operation, called a myringotomy, can usually be done on an outpatient basis by a surgeon, who is usually an otolaryngologist (a physician who specializes in the ears, nose, and throat). While the child is asleep under general anesthesia, the surgeon makes a small opening in the child's eardrum. A small metal or plastic tube is placed into the opening in the eardrum. The tube ventilates the middle ear and helps keep the air pressure in the middle ear equal to the air pressure in the environment. The tube normally stays in the eardrum for 6 to 12 months, after which time it usually comes out spontaneously. If a child has enlarged or infected adenoids, the surgeon may recommend removal of the adenoids at the same time the ear tubes are inserted. Removal of the adenoids has been shown to reduce episodes of otitis media in some children, but not those who are under 4 years of age. Research, however, has shown that removal of a child's tonsils does not reduce occurrences of otitis media. Tonsillotomy and adenoidectomy may be appropriate for reasons other than middle ear fluid.

Hearing should be fully restored once the fluid is removed. Some children may need to have the operation again if the otitis media returns after the tubes come out. While the tubes are in place, water should be kept out of the ears. Many physicians recommend that a child with tubes wear special ear plugs while swimming or bathing so that water does not enter the middle ear.

Resource #17 – MSN.com

In search engine, put in "ear infection" and "tubes." There were three sponsored links. Answers from the top three sites are below.

Site #1 – MedlinePlus: Ear Infections

In the list of articles and links, I clicked on the first link that was not under the news section. It was a link to the National Institutes of Health website that was visited previously. It is a fact sheet for parents (<http://www.nidcd.nih.gov/health/hearing/otitismedia.asp>):

What is otitis media?

Otitis media is an ear infection. Three out of four children experience otitis media by the time they are 3 years old. In fact, ear infections are the most common illnesses in babies and young children.

Are there different types of otitis media?

Yes. There are two main types. The first type is called acute otitis media (AOM). This means that parts of the ear are infected and swollen. It also means that fluid and mucus are trapped inside the ear. AOM can be painful.

The second type is called otitis media with effusion (fluid), or OME. This means fluid and mucus stay trapped in the ear after the infection is over. OME makes it harder for the ear to fight new infections. This fluid can also affect your child's hearing.

How does otitis media happen?

Otitis media usually happens when viruses and/or bacteria get inside the ear and cause an infection. It often happens as a result of another illness, such as a cold. If your child gets sick, it might affect his or her ears.

It is harder for children to fight illness than it is for adults, so children develop ear infections more often. Some researchers believe that other factors, such as being around cigarette smoke, can contribute to ear infections.

What's happening inside the ear when my child has an ear infection?

When the ears are infected the eustachian tubes become inflamed and swollen. The adenoids can also become infected.

The eustachian tubes are inside the ear. They keep air pressure stable in the ear. These tubes also help supply the ears with fresh air.

The adenoids are located near the eustachian tubes. Adenoids are clumps of cells that fight infections.

Swollen and inflamed eustachian tubes often get clogged with fluid and mucus from a cold. If the fluids plug the openings of the eustachian tubes, air and fluid get trapped inside the ear. These tubes are smaller and straighter in children than they are in adults. This makes it harder for fluid to drain out of the ear and is one reason that children get more ear infections than adults. The infections are usually painful.

Adenoids are located in the throat, near the eustachian tubes. Adenoids can become infected and swollen. They can also block the openings of the eustachian tubes, trapping air and fluid. Just like the eustachian tubes, the adenoids are different in children than in adults. In children, the adenoids are larger, so they can more easily block the opening of the eustachian tube.

Can otitis media affect my child's hearing?

Yes. An ear infection can cause temporary hearing problems. Temporary speech and language problems can happen, too. If left untreated, these problems can become more serious.

An ear infection affects important parts in the ear that help us hear. Sounds around us are collected by the outer ear. Then sound travels to the middle ear, which has three tiny bones and is filled with air. After that, sound moves on to the inner ear. The inner ear is where sounds are turned into electrical signals and sent to the brain. An ear infection affects the whole ear, but especially the middle and inner ear. Hearing is affected because sound cannot get through an ear that is filled with fluid.

How do I know if my child has otitis media?

It is not always easy to know if your child has an ear infection. Sometimes you have to watch carefully. Your child may get an ear infection before he or she has learned how to talk. If your child is not old enough to say, "My ear hurts," you need to look for other signals that there is a problem.

Here are a few signs your child might show you if he or she has otitis media:

- Does she tug or pull at her ears?
- Does he cry more than usual?
- Do you see fluid draining out of her ears?
- Does he have trouble sleeping?
- Can she keep her balance?
- Does he have trouble hearing?
- Does she seem not to respond to quiet sounds?

A child with an ear infection may show you any of these signs. If you see any of them, call a doctor.

What will a doctor do?

Your doctor will examine your child's ear. The doctor can tell you for sure if your child has an ear infection. The doctor may also give your child medicine. Medicines called antibiotics are sometimes given for ear infections. It is important to know how they work. Antibiotics only work against organisms called bacteria, which can cause illness. Antibiotics are not effective against viruses, such as those associated with a cold. In order to be effective, antibiotics must be taken until they are finished. A few days after the medicine starts working, your child may stop pulling on his or her ear and appear to be feeling better. This does not mean the infection is gone.

The medicine must still be taken. If not, the bacteria can come back. You need to follow the doctor's directions exactly.

Your doctor may also give your child pain relievers, such as acetaminophen. Medicines such as antihistamines and decongestants do not help in the prevention or treatment of otitis media.

How can I be sure I am giving the medicine correctly?

If your doctor gives you a prescription for medicine for your child, make sure you understand the directions completely before you leave his or her office. Here are a few suggestions about giving medicine to your child.

1. Read. Make sure the pharmacy has given you printed information about the medicine and clear instructions about how to give it to your child. Read the information that comes with the medicine. If you have any problems understanding the information, ask the pharmacist, your doctor, or a nurse. You should know the answers to the following questions:

- Does the medicine need to be refrigerated?
- How many times a day will I be giving my child this medicine?
- How many days will my child take this medicine?
- Should it be given with food or without food?

2. Plan. Sometimes it is hard to remember when you have given your child a dose of medicine. Before you give the first dose, make a written plan or chart to cover all of the days of the medication. Some children may require 10 to 14 days of treatment.

Put your chart on the refrigerator so you can check off the doses at every meal. Be sure to measure carefully. Use a measuring spoon or special medicine-measuring cup if one comes with the medicine. Do not use spoons that come with tableware sets because they are not always a standard size.

3. Follow Through. Be sure to give all of the medicine to your child. Make sure it is given at the right times. If your doctor asks you to bring your child back for a "recheck", do it on schedule. Your doctor wants to know if the ears are clear of fluid and if the infection has stopped. Write down and ask the doctor any questions you have before you leave his or her office.

Will my child need surgery?

Some children with otitis media need surgery. The most common surgical treatment involves having small tubes placed inside the ear. This surgery is called a myringotomy. It is recommended when fluids from an ear infection stay in the ear for several months. At that stage, fluid may cause hearing loss and speech problems. A doctor called an otolaryngologist (ear, nose, and throat surgeon) will help you through this process if your child needs an operation. The operation will require anesthesia.

In a myringotomy, a surgeon makes a small opening in the ear drum. Then a tube is placed in the opening. The tube works to relieve pressure in the clogged ear so that the child can hear again. Fluid cannot build up in the ear if the tube is venting it with fresh air.

After a few months, the tubes will fall out on their own. In rare cases, a child may need to have a myringotomy more than once.

Another kind of surgery removes the adenoids. This is called an adenoidectomy. Removing the adenoids has been shown to help some children with otitis media who are between the ages of 4 and 8. We know less about whether this can help children under age 4.

Site #2 - Home - CIPRODEX® Otic // Consumers & Patients

This is a manufacturer of a "topical antibiotic." On the page, there is information on why ear infections develop and the structure of the ear. Have to click on another link within the page to find an answer. Clicked no treatment options (http://www.ciprodex.com/consumer/treatment_options.asp):

Middle ear infections are among the most common illnesses experienced by young children. Acute otitis media (AOM) accounts for more doctor visits than any other disease and its incidence has steadily increased over the last few decades. It is also the most common reason children receive antibiotics or surgery.

Because topical drops cannot reach the middle ear when the eardrum is not perforated, oral antibiotics have been the primary form of AOM treatment. Oral (systemic) antibiotic therapy is generally prescribed without specific identification of the organism causing the infection. Instead, physicians usually select an antibiotic that is known to be effective against a broad range of common bacteria present in otitis media.

For recurring middle ear infections, some patients also require surgical implantation of ventilation tubes (also called ear tubes or tympanostomy tubes). Since ventilation tubes create an opening to the middle ear, topical antibiotic drops can be used for treatment once tubes are in place. Typically, infection that occurs in the middle ear after tubes are inserted is called acute otitis media with tympanostomy tubes (AOMT).

The development of bacterial resistance has caused researchers to review their approach concerning the best treatment for AOMT. The research targeting treatment options for AOMT has prompted a great deal of interest regarding the use of topical antibiotics such as CIPRODEX® Otic, a potent eardrop that's both safe and effective.

Site #3 - Ear infection guide - MayoClinic.com

This is a story from a mother's experience with her child's ear infections (<https://mayoclinic.com/health/ear-infections/EI99999/PAGE=E100020>):

Samantha had her first ear infection when she was 4 months old. "It was right after she stopped breast-feeding," recalls Samantha's mother, Bobbi.

Samantha didn't have another ear infection for six months, but this time it seemed like they would never end. "She had amoxicillin, and a week later, she had an infection in the other ear. We gave her amoxicillin again, and a week after that, it was in both ears. So we switched to Augmentin. It was about two months of constant ear infections."

Finally, Samantha's parents and doctor decided to try preventive antibiotics to see if they would help alleviate her ear infections.

After about three weeks, Bobbi says she felt that the preventive antibiotics approach wasn't helping. "Samantha was really cranky and wasn't sleeping. She was walking, but she wasn't steady on her feet." A hearing (audiology) test indicated that Samantha's hearing was fine. But she continued to have fluid in her middle ear, although it wasn't infected. After talking it over with their doctor, Samantha's parents made their decision. "It seemed like the only way to get the fluid out of her ears and stop the infections was to have tubes," explains Bobbi.

In the first four months with the tubes in both ears, Samantha had two more ear infections. "I was shocked when she got another infection," says Bobbi. "I expected that with the tubes, she would never get ear infections again." In addition, one of the tubes started to come out, and their doctor told them that Samantha may need to have another set of tubes. Despite these surprises, Bobbi says that she's completely satisfied that she and her husband, Jim, made the right decision for their daughter.

Editor's note: Since first sharing their story in 2000, a second set of ear tubes was placed in Samantha's ears. A surgeon also removed her adenoids — lymphatic tissues located in the throat. Since then Samantha has had only one ear infection. Bobbi credits the tubes and adenoid removal for minimizing ear infections.

To the left, there were links to treatment options. I clicked on this link (<https://mayoclinic.com/health/ear-infections/EI99999/PAGE=E100013>):

Some children need ear tubes to resolve repeated ear infections. The point at which you consider ear tubes is up to you and your doctor.

Reasons for ear tubes

Your child may require ear tubes if he or she has had:

- Middle ear fluid for more than four months and has temporary hearing loss as a result
- Recurrent ear infections that don't respond to antibiotics
- An ear infection that caused structural damage to the tympanic membrane or middle ear
- Delays in speech development due to chronic middle ear fluid

How is it done?

Surgeons usually perform this operation (myringotomy) while the child is under general anesthesia, and it usually takes about 10 minutes to insert the tube. The entire procedure — including the preparation time, anesthesia, surgery and recovery — takes about half a day.

Through the ear canal, the surgeon uses delicate instruments to make a small incision in the eardrum. The incision may be made with a small scalpel or laser — a focused ray of light used to create a hole.

The surgeon then inserts a tiny metal or plastic tube into the hole in the eardrum. This tube helps drain the fluid, ventilate the middle ear, and balance the pressure between the outer and middle ear.

Usually, ear tubes stay in the eardrum for six to 12 months and then fall out on their own as the child's eardrum grows. Rarely, the tube doesn't come out of the eardrum and needs to be surgically removed.

Even with ear tubes, some children may still get an occasional ear infection. In some cases, the ear tube falls out too soon and a second set needs to be put in.

Surgery risks

Surgery for ear tube placement carries certain risks, including:

- Bleeding and infection
- Persistent drainage of fluid
- Tearing or scarring of the eardrum
- Infection of the tubes themselves

General anesthesia carries some risks as well, such as an allergic reaction and breathing difficulties. Your doctor first does a checkup to make sure there's no family history of problems using anesthesia and to check your child's health. Risks are usually very low.

After the procedure

Children generally recover from ear tube placement surgery fairly quickly. It may take a few hours for your child to fully recover from the effects of anesthesia. He or she will likely be sleepy and irritable for the rest of the day after surgery. Most children don't need to stay overnight in the hospital. And in most cases, children resume regular activities within 24 hours of the surgery.

A child's hearing usually improves immediately after surgery.

You may see drainage from your child's ear for up to one week after the surgery. This is normal. Drainage may appear as crusted material or as dripping liquid. The color of the drainage may be clear, green, yellow, brown, pink or bloody. After surgery, your doctor may prescribe eardrops to prevent buildup of blood or other fluids in the tube.

You may need to take precautions to protect the ear and the tube when your child is swimming or bathing. Discuss possible restrictions and water protection options with your doctor.

Appendix #10

Query #5: Alzheimer's Disease

Resources: 2, 3, 4, 5, 9, 10, 11, 14, 15, 16, 17

Resource #2 – Health Canada – It's Your Health

Clicked on "Diseases and Conditions" at the left-hand side of page. Clicked on "more conditions" In the list, clicked on Alzheimer's. New window opened: National Advisory Council on Aging (http://www.naca-ccnta.ca/position/23_alzheimer/index.htm)

Answer:

2.1 Alzheimer Disease

Alzheimer Disease is a progressive, irreversible degenerative disease of the brain resulting from certain changes to the regions of the brain responsible for memory, language, judgement, reasoning and abstract thinking. It is characterized by shrinkage of the brain due to loss of cell tissue and the presence of fibres called tangles and the accumulation of plaques. These plaques are formed in the brain by proteins that usually exist in soluble form, but for reasons unknown, aggregate and form solid deposits. The plaques and tangles, first identified by Dr. Alois Alzheimer, are now known as indicators of AD, though scientists are still not certain whether they are a cause or an effect of the disease.

There are two forms of AD:

- Sporadic Alzheimer Disease (90-95% of all cases); and
- Familial Autosomal Disease (FAD: 5-10%).

Sporadic AD, the most common form, typically develops in people over age 65; in fact, most cases are in individuals age 85 and older. People with sporadic AD may or may not have a history of AD in their family, but a child of a parent who has this form of AD has a higher risk of developing AD than someone with no family history of the disease. Familial autosomal dominant AD, or FAD, is a rare form of the disease and makes up only 5-10% of all cases of AD.⁷ It occurs in families in which a mutated gene is passed from generation to generation. If a parent has the mutated gene, each child has a 50% chance of inheriting the gene; the presence of the gene means the individual will eventually develop the disease - usually at a younger age than the sporadic form of AD.

There is no definitive test to determine if a living person has AD. Rather, the diagnosis is made by a thorough clinical assessment that confirms symptoms and rules out other possible causes (e.g., depression, thyroid problems, medication side-effects). It can be done by a trained family physician but may require referral to a memory clinic or to specialists such as neurologists, psychiatrists, or geriatricians. A properly performed assessment can accurately confirm or rule out a diagnosis of AD 80-90% of the time. The only definitive way of diagnosing AD is to perform brain autopsy after death.

3.3 Treatment of Alzheimer Disease

While there is no cure for Alzheimer Disease, some treatments can retard or reduce certain symptoms. Research is ongoing to find new treatments.

3.3.1 Current treatments

In Canada, there are currently three medications which help alleviate the symptoms and appear to possibly slow the neurocognitive and/or behavioural decline in some patients:

- Aricept (donepezil);
- Exelon (rivastigmine); and
- Reminyl (galantamine hydrobromide).

These three medications are useful in treating mild to moderate AD. Potential benefits from these drugs include improved cognition (memory, language and orientation) and ability to function in daily activities. Sometimes, the benefits from these medications are seen in improved behaviour rather than improved memory. This can be significant, not only for the patient, but especially for the caregiver because it is often disturbing behaviour that proves most troubling for the caregiver.

Current medications have marked limitations: they do not work for everyone; their benefits are temporary (but may be effective for considerable periods of time); and, after maximum benefits have been reached, there is a slow decline over the next year back to the condition prior to treatment. Yet, for those treated with these medications, there seems to be a slower rate of further decline after one year of treatment than in those who did not receive treatment. A new drug (memantine) to treat moderate to severe AD is being investigated in Canada. Memantine is currently in Phase 3 of clinical trials, the last stage prior to approval for use.

Other drugs such as anti-depressants, anti-anxiety and anti-psychotics are used to treat some of the disturbing symptoms of AD but do not specifically target AD.

3.3.2 Additional treatments under investigation in Canada

A great deal of research in Canada and other countries continues to investigate the possibility of other treatments:

- vitamin E;
- omega-3 fatty acids;
- ginkgo biloba, antioxidants, caffeine, nicotine;
- non-steroidal anti-inflammatories;
- anti-cholesterol drugs (statins);
- stem cells to replace dead neurons;
- drugs to prevent plaques in brain; and
- estrogen (evidence is mixed on benefits/drawbacks).

Resource #3 – MediResource

This is the Health and Fitness feature of Sympatico-MSN.

Clicked on "Disease Library. "Clicked on "Agree" under terms and conditions. From alphabet clicked on "A." Clicked on "Alzheimer's" (http://mediresource.sympatico.ca/disease_detail.asp?disease_id=218).

Answer:

Symptoms and Complications

Mild forgetfulness is normal with advancing age, but healthy older people are usually good at remembering what's most important to them. There is reason for concern if they start forgetting what they were just doing, get lost in their own neighbourhood, or start displaying uncharacteristic or inappropriate behaviour. If your husband is always misplacing his keys, it may mean nothing. If he starts leaving them in the fridge or the sugar bowl, it may be cause for concern.

One of the most recognizable symptoms of Alzheimer's disease is a speech problem, such as a person choosing the wrong words, or not understanding simple sentences. Problems with numbers are also common. These are the most reliable signs of early-stage Alzheimer's disease. Other early signs include forgetfulness about recent events (loss of short-term memory), trouble with tasks such as housework or balancing a chequebook, and poor judgment.

In the later stages, people with Alzheimer's disease begin to have trouble caring for themselves and recognizing friends or loved ones. They may become confused, agitated, or aggressive.

The Alzheimer's Society of Canada lists these 10 warning signs to be aware of:

- memory loss affecting day-to-day functioning
- difficulty performing familiar tasks
- problems with language
- disorientation of time and place
- poor or decreased judgment
- problems with abstract thinking
- misplacing things
- changes in mood and behaviour
- changes in personality
- loss of initiative

Making the Diagnosis

Unfortunately, there's still no safe, definitive test for Alzheimer's disease. The diagnosis is made based on the type and progression of symptoms and by eliminating the many other possible causes of dementia, which include:

- vascular dementia - caused by small strokes that damage brain tissue
- nutritional and vitamin deficiencies, such as pernicious anemia or pellagra
- liver, kidney, heart, lung, or thyroid disease, which can all cause temporary or permanent mental impairment
- dementia pugilistica - "boxer's brain," caused by repeated head trauma
- Parkinson's disease, Huntington's disease, or end-stage multiple sclerosis - Parkinson's in particular can be hard to distinguish from Alzheimer's disease, as they share many symptoms
- depression - this very treatable condition is sometimes mistaken for Alzheimer's disease
- medications - several medications can cause symptoms (e.g., agitation, confusion, or disorientation) that look like Alzheimer's disease. These medications include some pain medications and certain medications used for depression or anxiety. Talk to your doctor or pharmacist to find out whether a medication you or a loved one is taking could cause these symptoms.

These and other possible causes of dementia can mostly be identified with a few tests and questions. If the symptoms of Alzheimer's are present, and there's no other explanation for them, the physician will give a diagnosis of "probable Alzheimer's disease." Don't cling to false hopes if you or a loved one get this diagnosis - it's right 9 times out of 10.

Treatment and Prevention

Because there is currently no cure for Alzheimer's disease, treatment focuses on relieving symptoms and maintaining the quality of the person's life. Certain medications can help maintain brain function. However, the course of the disease is such that it eventually continues to worsen.

Fortunately, there are a number of ways to help people with Alzheimer's disease that do not involve medications. These include:

- reminder notes
- personal organizing tools, such as date books and beepers
- providing instructions for activities such as bathing, eating, and dressing
- family counselling and support
- behaviour training for inappropriate behaviours

The behaviour changes of Alzheimer's disease can be very distressing to people and their families or caregivers. Medications may be used to control severe agitation or behaviours which may result in physical harm or are very distressing to the person. However, in many cases agitation can be controlled without medications.

Not enough is known about the causes of Alzheimer's to provide clear advice about how to prevent it. Research into the effects of tobacco and alcohol is just getting underway, but there's still no hard evidence one way or the other. These drugs are clearly linked to other forms of dementia, however - it's a good idea for people who want their brains to stay healthy to avoid both.

Contact your local Alzheimer's society for more information on new advances in research and suggestions for helping a person who has Alzheimer's disease.

Resource #4 – MedBroadcast

Clicked on "A" in alphabetic index. Then clicked on Alzheimer's Disease. Next page, clicked on Alzheimer's
(http://www.medbroadcast.com/channel_section_details.asp?text_id=2102&channel_id=1008&relation_id=4995):

Answer:

10 Warning Signs of Alzheimer's Disease (from Alzheimer Society:
www.alzheimer.ca/english/disease/warningsigns.htm)

1. Worsening memory loss for day-to-day activities, such as names, phone numbers, recent events
2. Loss of ability to perform certain familiar tasks
3. Forgetting simple words, sometimes replacing them with less appropriate words
4. Disorientation in time and place, becoming lost and not knowing how to get home
5. Worsening judgement, such as dressing inappropriately for the weather or not seeking help for a serious problem
6. Losing abstract reasoning, such as understanding the significance of events or the ability to understand a principle
7. Misplacing things, even placing things in strange places, sometimes becoming paranoid or suspicious because they have disappeared
8. Rapid mood swings for no apparent reason
9. Personality change, becoming apathetic, confused, suspicious or fearful
10. Loss of initiative, to the point the person may not spontaneously engage in any activities

There is currently no specific clinical test or procedure that can definitively diagnose Alzheimer's Disease (AD). AD is therefore considered a diagnosis of exclusion - that is, the many other causes of dementia must be ruled out by thorough evaluation before the clinical diagnosis of AD can be made. This will involve a doctor:

- obtaining a detailed history,
- conducting a physical (including neurological) examination,
- testing intellectual functioning (often referred to as a cognitive assessment or mental status exam), and
- ordering various laboratory tests and usually some form of diagnostic neuroimaging procedure.

The evaluation process for the detection of treatable dementia follows the following steps:

1. Patient history
2. Physical Examination
3. Cognitive Assessment
4. Laboratory Results
5. Diagnostic Neuroimaging
6. Clinical Diagnosis

The reason a thorough evaluation is so important is that sometimes other treatable causes of dementia are detected. For example, although AD can not be definitively diagnosed on the basis of a specific laboratory test, laboratory testing may reveal that someone's confusion is secondary to a thyroid disorder. Similarly, none of the 4 major diagnostic neuroimaging techniques can be utilized to definitively diagnose AD.

These tests are:

- computerized tomography (CT)
- magnetic resonance imaging (MRI)
- single photon emission computerized tomography (SPECT)
- positron emission tomography (PET)

Although each technique can yield images consistent with AD, the greater diagnostic value of neuroimaging currently resides in its ability to diagnose a number of other causes of dementia that can mimic AD. For example, an MRI scan may establish that someone's confusion is due to a blood clot.

Recently, the potential use of genetic tests to diagnose Alzheimer's Disease has emerged. This is limited to a number of extremely rare families where virtually one out of two individuals is affected with AD. Genetic testing in these circumstances should be confined to research centers. There is also now evidence that testing for the various forms of a gene called APOE (apolipoprotein E) may help support the diagnosis of AD. Like APOE, many other potential diagnostic tests have been proposed but the role of these tests in clinical practice is still being clarified.

Ultimately, a definitive diagnosis of AD requires confirmation of the diagnosis by brain biopsy or autopsy. Doctors sharing diagnostic impressions with patients and their families should emphasize that the clinical diagnosis of AD is a 'probable' rather than a 'definitive' diagnosis.

At this time, there is no cure for Alzheimer's Disease (AD). However, it can be treated. Treatments for Alzheimer's Disease include:

- prescription medications to treat some Alzheimer's disease symptoms (more information below)
- treatment of coexisting medical or psychiatric illnesses that can aggravate the symptoms of AD
- safety measures to reduce the risk of injury caused by symptoms (such as recognizing the risk for wandering or unsafe driving)
- preserving the best possible quality of life for the affected person by providing companionship, secure living space, and the opportunity to use their remaining abilities

A number of prescription medications are available to help treat the symptoms of Alzheimer's disease. One group of medications, the cholinesterase inhibitors (including donepezil [Aricept®], galantamine [Reminyl®], and rivastigmine [Exelon®]), is used for mild to moderate Alzheimer's disease. These medications work by increasing the levels of acetylcholine in the brain. Researchers believe that Alzheimer's disease is related to a decrease in the number of nerve cells that make acetylcholine, a neurotransmitter (chemical messenger) in the brain. Increasing the level of acetylcholine helps relieve the symptoms of Alzheimer's disease.

A new medication known as memantine [Ebixa®] is now available for moderate to severe Alzheimer's disease. It belongs to the group of drugs known as the NMDA receptor antagonists. This type of medication works by blocking a substance called glutamate in the brain. High glutamate levels are believed to play a role in Alzheimer's disease.

None of the medications available today can cure Alzheimer's disease. They can only help treat the symptoms. However, even symptom relief can go a long way towards helping people with Alzheimer's disease and their caregivers.

Support for the caregiver of someone with Alzheimer's disease is another important part of the treatment plan. This involves providing information about AD, including the available community resources such as the local Alzheimer Society. It is extremely important that caregivers also obtain relief - time on their own is essential in order to re-energize for the caregiving ahead.

Resource #5 – Mayo Clinic

Clicked on "A" under "find it fast." Chose Alzheimer's (<http://www.mayoclinic.com/health/alzheimers-disease/DS00161>).

Answer:

Signs and symptoms

Everyone has occasional lapses in memory. It's often quite normal to forget the names of people whom you rarely see. But it's not a normal part of aging to forget the names of familiar people and objects.

Alzheimer's disease — which is a progressive, degenerative brain disease — goes beyond simple forgetfulness. It may start with slight memory loss and confusion, but it eventually leads to irreversible mental impairment that destroys a person's ability to remember, reason, learn and imagine.

Most people with Alzheimer's share certain signs and symptoms of the disease. These may include:

- Increasing and persistent forgetfulness. At its onset, Alzheimer's disease is marked by periods of forgetfulness, especially of recent events or simple directions. But what begins as mild forgetfulness persists and worsens. People with Alzheimer's may repeat things and forget conversations or appointments. They routinely misplace things, often putting them in illogical locations. They frequently forget names, and eventually, they may forget the names of family members and everyday objects.
- Difficulties with abstract thinking. People with Alzheimer's may initially have trouble balancing their checkbook, a problem that progresses to trouble recognizing and dealing with numbers.
- Difficulty finding the right word. It may be a challenge for those with Alzheimer's to find the right words to express thoughts or even follow conversations. Eventually, reading and writing also are affected.
- Disorientation. People with Alzheimer's may lose a sense of time and dates. They may find themselves lost in familiar surroundings. Eventually, they may even wander from home.
- Loss of judgment. Solving everyday problems, such as knowing what to do if food on the stove is burning, becomes increasingly difficult, eventually impossible. Alzheimer's is characterized by greater difficulty in doing things that require planning, decision making and judgment.
- Difficulty performing familiar tasks. Once-routine tasks that require sequential steps, such as cooking, become a struggle as the disease progresses. Eventually, people with advanced Alzheimer's may forget how to do even the most basic things.
- Personality changes. People with Alzheimer's may exhibit mood swings. They may express distrust in others, show increased stubbornness and withdraw socially. Early on, this may be a response to the frustration they feel as they notice uncontrollable changes in their memory. Depression often coexists with Alzheimer's disease. Restlessness also is a common sign. As the disease progresses, people with Alzheimer's may become anxious or aggressive and behave inappropriately.

Typically, loved ones notice very gradual — not sudden — changes in a person with Alzheimer's. As the disease progresses, signs and symptoms become serious and noticeable enough to cause people with Alzheimer's or their family members to seek medical help. Many people with Alzheimer's disease realize that something is happening to their memory, which is often frightening.

The course the disease takes and how rapidly changes occur vary from person to person. The average survival rate is eight years after being diagnosed with Alzheimer's, but some people live as few as three years after diagnosis, while others live as long as 20 years.

Alzheimer's generally progresses from mild to moderate to severe to, finally, profound impairment. People with mild Alzheimer's can usually live alone and function fairly well. Those with moderate Alzheimer's may have greater difficulty coping without supervision. People with advanced Alzheimer's generally can no longer care for themselves.

Alzheimer's and other cognitive conditions

Researchers have identified a state of memory loss called mild cognitive impairment, which could potentially be known as a pre-Alzheimer's period. This memory loss falls somewhere between what's associated with normal aging and what's common in Alzheimer's disease. People with mild cognitive impairment may experience forgetfulness beyond what's typical for their age, yet they don't have the dementia of Alzheimer's. Identification of this category of memory loss could help doctors more accurately diagnose, advise and treat these people. It could also alert these people to a greater risk of developing Alzheimer's disease.

In the past, people called dementia senility and considered it an inevitable part of aging. Doctors now know that dementia isn't a normal part of aging and that it's caused by some underlying condition affecting the brain. While Alzheimer's is one of the most common causes, many different conditions can cause dementia. Some are treatable, such as depression. That makes it important to diagnose the particular signs and symptoms of dementia and attempt to identify its underlying cause.

Screening and diagnosis

There's no one test to diagnose Alzheimer's disease. Instead, doctors diagnose Alzheimer's disease through a process of elimination —ruling out other diseases and conditions that also can cause memory loss.

Small, undetected strokes, for example, can cause dementia by temporarily interrupting blood flow to the brain. People with Parkinson's disease, a degenerative nerve disease, also can develop dementia. Depression can cause

lapses in memory. In addition, many older adults are on multiple medications that may impair their ability to think clearly.

To help distinguish Alzheimer's disease from other causes of memory loss — which are often treatable — doctors typically rely on the following:

- **Medical history.** Doctors may ask about a person's general health and past medical problems. They'll want to know about any problems a person may have in carrying out daily activities. If possible, doctors will also want to speak with a person's family or friends to get more information.
- **Basic medical tests.** Blood and urine tests may be done to help doctors rule out other potential causes of the dementia. In some cases, testing a small amount of spinal fluid may help.
- **Mental status evaluation.** These tests screen memory, problem-solving abilities, attention spans, counting skills and language. They help doctors pinpoint specific problems a person may have with cognition. For instance, doctors might test recent and long-term memory by asking: What day is it today? Or: When was World War II? Recall tests are another example. Doctors may list familiar objects, and then ask a person to repeat them immediately, and again five minutes later.
- **Neuropsychological testing.** Sometimes doctors undertake a more extensive assessment of memory, problem-solving abilities, attention spans, counting skills and language. This is especially helpful in trying to detect Alzheimer's and other dementias at an early stage. Doctors use formal psychological tests to determine if a person's mental abilities are as expected for his or her age and education. The patterns of any mental deficits observed during neuropsychological testing can help doctors sort out possible causes of dementia.
- **Brain scans.** Doctors may want to take a picture of the brain using a brain scan. Several types of brain scans are available — including a computerized tomography (CT) scan, a magnetic resonance imaging (MRI) scan and a positron emission tomography (PET) scan. By looking at a picture of the brain, doctors may be able to pinpoint any visible abnormalities. Researchers are studying whether brain scans can eventually be used to detect an increased risk of Alzheimer's in healthy people before symptoms begin.

Using the methods above, doctors can accurately diagnose 90 percent of Alzheimer's cases. Alzheimer's can be diagnosed with complete accuracy only after death, using a microscopic examination of brain tissue, which checks for plaques and tangles.

Genetic testing for Alzheimer's is in its beginning stages. Blood tests are available that can tell whether a person carries the genetic mutations believed to be associated with Alzheimer's, but the tests can't tell who will or will not get the disease.

Treatment

Currently, there's no cure for Alzheimer's disease. Medications and caregiving are the primary treatments.

Medications

Current medications for Alzheimer's can't stop or reverse the underlying disease process. But they may slow it down, lessening signs and symptoms. Medications commonly recommended for people with mild to moderate Alzheimer's include:

- **Cholinesterase inhibitors.** This group of medications, which includes donepezil (Aricept), rivastigmine (Exelon) and galantamine (Reminyl), works by improving the levels of neurotransmitters in the brain. Research published in April 2005 in the *New England Journal of Medicine* indicates that donepezil (Aricept) additionally can delay, although not prevent, the onset of Alzheimer's disease. Researchers believe that delaying or slowing Alzheimer's is an important step in fighting the disease. About half of people taking cholinesterase inhibitors have some improvement in their signs and symptoms.
- **Memantine (Namenda).** In October 2003, the Food and Drug Administration approved the drug memantine (Namenda), the only medication specifically indicated for treatment of moderate to severe stages of Alzheimer's. Memantine seems to slow the loss of daily living skills, such as dressing and going to the bathroom. The drug works by protecting brain cells from damage caused by the chemical messenger glutamate.

Doctors also sometimes prescribe drugs to improve behavioral symptoms that often accompany Alzheimer's, including sleeplessness, wandering, anxiety, agitation and depression.

Today, treatment of Alzheimer's disease is still in its infancy. But researchers are hoping that new medications will be available that do more than treat the symptoms of Alzheimer's. Some recent studies have found success using immune globulins to reduce the amount of beta-amyloid in the brain, while other researchers have produced drugs that stop or at least inhibit the production of beta-amyloid.

Caregiving

Until there's a cure for Alzheimer's, people with the disease will need caregiving. According to the Alzheimer's Association, approximately one in 10 families has a relative with Alzheimer's disease. Of the 4 million people with Alzheimer's disease in the United States, the majority live at home — often receiving part- or full-time care from family members.

Caregiving can be a challenge. The slow and unpredictable decline that may last more than a decade requires caregivers to exercise patience, understanding, compassion, and often, creativity.

The key to caregiving is focusing on things that the person with Alzheimer's can still do and enjoy. In fact, learning ways to reduce the impact of impaired abilities and behavior problems can help avoid some of the most difficult aspects of the disease.

Each person with Alzheimer's disease experiences symptoms and progression differently. Consequently, the techniques to care for each person should vary. You may have to adapt the following tips to your specific caregiving situation:

- Use memory aids. Memory aids may help a friend or family member remain independent. Write out a list of the day's activities, the phone numbers that can be used to call for help, and instructions on how to do simple tasks, such as make a cup of tea or use the telephone.
- Provide structure. A home environment that provides serenity and stability reduces behavior problems. New situations, noise, large groups of people, being rushed or pressed to remember, or being asked to do a task that's too difficult can cause anxiety. As a person with Alzheimer's becomes upset, the ability to think clearly declines even more.
- Monitor wandering. Wandering is a common problem. In some cases, a pocket card with simple instructions, such as "Call home" (with a phone number below), may help. Make sure your loved one wears a bracelet with his or her name, phone number and a notation such as "Memory impaired." The Alzheimer's Association, which has a 24-hour hot line — (800) 272-3900 — offers this resource through its national Safe Return Program. Also try to determine the cause of wandering. It may simply be a signal that the person with Alzheimer's is looking for something, such as a bathroom, or is seeking a meaningful activity or reassurance. Some experts believe taking your loved one for a vigorous daily walk helps reduce wandering.
- Establish a nighttime ritual. Behavior is often worse at night. Try to establish going-to-bed rituals that are calming and away from the noise of television, meal cleanup and active family members. Leave night lights on to prevent disorientation. Limiting caffeine during the day, discouraging daytime napping and offering opportunities for exercise during the day may help prevent nighttime restlessness.
- Enhance communication. When talking with your loved one, stand where you can be seen and touch his or her arm or shoulder to focus attention. Speak slowly, in simple sentences and don't rush the response. Present only one idea or instruction at a time. Use gestures and cues, such as pointing to objects. Avoid asking questions or offering difficult choices because trying to come up with answers may prove frustrating.
- Create a safe environment. Make your home familiar and safe. Keep furniture in the same place to avoid clutter and help prevent falls. Install locks on cabinets containing medicines, alcohol, guns, toxic substances, and dangerous utensils and tools. Remove electrical appliances from your bathroom to prevent shocks, set your water heater no higher than 120 F to prevent scalding, and install grab rails to prevent falls.
- Encourage exercise. Exercise carries many benefits for someone with Alzheimer's disease. The fact that these benefits often are the same for people without Alzheimer's disease doesn't lessen their importance. In fact, it just makes exercise a more important activity for caregivers and people with Alzheimer's to engage in together. The main benefits of exercise include improved strength and cardiovascular health. Exercise can also lessen symptoms of depression and help retain motor skills, create a calming effect. It can also help sustain strength, flexibility and balance — which may lessen the risk of serious injury from a fall.

In addition to helping someone with Alzheimer's deal with daily challenges, family members and loved ones should begin to try to answer practical, long-term questions about caregiving as soon as possible. These questions may involve personal, legal and financial issues. Some examples might include:

- Level of self-sufficiency. How long can a person with Alzheimer's safely drive, work or live alone?
- Who's available and able to help. Can family or friends provide the care necessary for the current phase and during later progression of the disease?
- Financial resources. Is money available for professional in-home care or a care facility now or in the future if the need arises?

It's important for people with Alzheimer's, their doctors and their families to discuss these matters early on in the disease. In general, people with Alzheimer's should be afforded as much independence as is safely possible and for as long as possible.

Resource #9 – Canadian Health Network

In search function, put in Alzheimer's Disease. Answers from the top three sites are below.

Site #1 – Heretohelp.bc.ca. Various agencies and organizations in BC came together to provide health information to the public (<http://www.heretohelp.bc.ca/publications/factsheets/alzheimers.shtml>).

Describes Alzheimer's, but no specific information on diagnosis or treatment. Gives 10 warning signs.

Top 10 Warning Signs

Remember that it's normal to occasionally forget appointments, someone's name, or where you put your glasses. But if you notice some of the signs below interfering with daily life, talk to your doctor.

- Memory loss (particularly of recent events) that affects day-to-day function
- Difficulty performing familiar tasks
- Problems with language, such as forgetting simple words or substituting words
- Disorientation of time and place (for longer than a moment)
- Poor or decreased judgment
- Problems with abstract thinking
- Misplacing things, particularly in inappropriate places
- Changes in mood and behaviour
- Changes in personality including confusion, withdrawal, fearfulness
- Loss of initiative

Site #2 – Your Health from Calgary Health Region. Provides more of a description of the disease (<http://yourhealth.calgaryhealthregion.ca/Topic.jsp?GUID={F4A3CA5D-1A3F-40D7-BF2D-9FE082153F09}>).

Description

Alzheimer's disease is a condition that causes progressive deterioration of brain functions. Symptoms include the gradual loss of memory, reason, language and the ability to care for oneself. In order to understand what Alzheimer's disease is and is not, it is important to get some terms straight. A number of different factors can contribute to the development of "dementia". Dementia means a loss of mental functioning. Alzheimer's disease is only one type of dementia. It is, however, the most common cause of dementia. Dementia and Alzheimer's disease are not the same as "senility". Senility is really just the term used to refer to the mild slowing down of mental functioning, decreased memory and reduced concentration that happens to most of us as we get older.

The diagnosis of Alzheimer's disease is based on:

- a thorough medical examination
- mental function testing
- a thorough personal and family history

- the exclusion of other possibilities (such as hypothyroidism, vitamin B deficiency, depression, a head injury, a brain tumor or bleeding in the brain)
- an EEG which may show slowed brain waves
- a CT scan which may show a reduction in size of the cerebrum
- a brain biopsy (in some cases)

Often a definite diagnosis of Alzheimer's is not made until after death. Autopsy results can show "loss of nerve cells, specks of brain debris and tangles of nerves that resemble pieces of unwound string".

The cause of Alzheimer's disease is not clear. While extensive research into Alzheimer's disease is underway, at the present time we have no effective ways to prevent or treat the disease. The goals for caring for someone with Alzheimer's are:

- to help minimize and control symptoms
- provide supportive care
- prevent injury to the person with Alzheimer's or others

In the early stages of the disease, people suffering from Alzheimer's can often be cared for at home with appropriate support and monitoring. As mental functioning deteriorates, however, reasoning and memory become impaired to the point where it is not safe to leave the person unattended. In situations such as these, the day-to-day care of someone with Alzheimer's can take a tremendous physical and emotional toll on caregivers.

Site #3 – Canadian Medical Association. Is a PDF document on managing Alzheimer's disease. Only discusses treatment

(http://www.cma.ca/multimedia/CMA/Content/Images/Inside_cma/WhatWePublish/LeadershipSeries/English/pg29EC.pdf)

Treatment

Currently, in Canada, four medications are approved by Health Canada for the treatment of AD. The cholinesterase inhibitors (ChEIs) — donepezil, galantamine and rivastigmine have been available for some time for the treatment of mild to moderate AD. More recently, memantine, a glutamate receptor antagonist, was approved for the treatment of moderate to severe AD. All of these treatments provide symptomatic relief and are not disease modifying. Their effects are modest, yet modest gains in a progressive neurodegenerative disease are viewed as meaningful by patients and their families.

In numerous randomized clinical trials (RCTs), ChEIs have consistently been shown to improve or delay the decline of cognitive functioning, delay the emergence of challenging behaviours and slow the loss of activities of daily living. In RCTs, benefits have been shown to last over a period of up to 2 years, with data from open-label trials suggesting a longer benefit.³ The effect of ChEIs on specific behaviours is less clear, as clinical research tools used to measure behaviour lump together a variety of different behaviours, making it difficult to appreciate which ones respond to cholinergic medications. Some evidence seems to suggest an improvement in terms of apathy and hallucinations but there is no evidence to suggest a role for ChEIs in the treatment of agitation and aggression. ChEIs may also have a role in delaying the emergence of behaviours and, in 1 study, discontinuation of donepezil in patients with behavioural symptoms led to a worsening of behaviour and an increase in caregiver distress.⁴ Evidence for pharmacoeconomic benefits and delay of admission to an institution with ChEIs is less compelling. The Canadian consensus guidelines for the treatment of AD state that these drugs should be offered to every patient with mild to moderate AD.⁵ Before initiating treatment, physicians should discuss reasonable expectations with the patient and their caregiver.

Options

Patients should be warned of possible side effects, noting that they are often mild and fleeting. Patients should be advised to discontinue treatment if they experience protracted nausea, vomiting or other intolerable side effects. Although there is little evidence to support switching ChEIs, this is likely a safe and reasonable option for patients who are experiencing intolerable side effects or who are felt to be not responding. Determining the benefit from these drugs in individual patients in clinical practice can be challenging.

Administration of the mini-mental status examination (MMSE) to measure cognitive changes is mandatory under most provincial drug benefit plans, but clinicians should also be encouraged to monitor behaviour and activities of daily living in addition to cognition. The goal assessment scale (GAS) is a useful clinical tool for monitoring response to treatment.⁶ Memantine is also a symptomatic treatment, with modest benefits in the domains of

cognition, behaviour and activities of daily living. A placebo-controlled study looking at the combination of donepezil and memantine in patients with moderate to severe AD showed greater benefit from the combination than from donepezil alone.⁷ Given the “floor effect” of the MMSE in the later stages of dementia, it is difficult for clinicians to determine a cognitive benefit from memantine in their patients using this tool. At this time, memantine has not been listed by any of the provincial drug formularies.

Concomitant cerebrovascular disease has been shown to exacerbate the expression of AD; therefore, it makes sense to monitor and control cardiovascular risk factors in patients with AD.⁸ Excessive use of alcohol should be discouraged. Challenging behaviours, such as verbal and physical aggression, invariably occur in most patients with AD, placing a tremendous burden on caregivers and often leading to caregiver burnout and admission of the patient to long-term care. Managing these behaviours can be difficult, even for the most experienced clinician. Efforts to identify triggers that evoke disturbing behaviours can often yield more favourable results than pharmacologic therapies. Patients exhibiting challenging behaviours should be fully assessed for medical morbidity, such as delirium and pain. Caregivers should be counseled on how to approach and communicate with individuals with dementia, and attempts should be made to implement non-pharmacologic strategies to treat the behaviour before considering the prescription of drugs. The use of non-pharmacologic and pharmacologic strategies need not be exclusive of each other.

Since the 1950s, neuroleptic drugs have been the mainstay of treatment for Alzheimer patients with agitated and aggressive behaviours. Meta-analyses of both conventional and atypical antipsychotics have shown that these drugs have a modest effect in decreasing the severity and frequency of these behaviours.^{9,10} The atypical neuroleptics offer a significantly lower risk of extrapyramidal and anticholinergic side effects than conventional neuroleptics. A number of studies with 2 of these agents, risperidone and olanzapine, have demonstrated that they are effective and well tolerated in the treatment of aggression, agitation and psychosis in patients with AD. However, the recent warnings from the Food and Drug Administration and Health Canada reporting a 1.6-1.7 increased risk of mortality in AD patients treated with atypical neuroleptics have made the ongoing use of these medications a topic of hot debate.¹¹

Clinicians who continue to prescribe these drugs should be especially cautious when treating patients with a history of cerebrovascular disease and cardiac conduction abnormalities. Because challenging behaviours often diminish over time, attempts to decrease the dose or discontinue the drug should be considered. Antidepressants, especially citalopram and trazodone, are sometimes used to treat symptoms of agitation, especially when anxiety and depression appear to be an underlying cause. Short-acting benzodiazepines, such as lorazepam, may be considered as a when-needed treatment for acute agitation or as a sedative in preparation for a procedure, but should be avoided as a scheduled treatment. Other medications, such as anti-convulsants and hormonal therapies, are occasionally used as second— or third-line treatments.

Resource #10 – NS Health Network

Searched for Alzheimer’s Disease. The second hit was on Parkinson’s disease, therefore it is not relevant. The third hit was a commercial resource, therefore it is not relevant.

Site #1 – Alzheimer’s Foundation of America (<http://www.alzfdn.org/>). Clicked on “About Alzheimer’s.”

Symptoms

- Symptoms are divided into two categories: cognitive, or intellectual, and psychiatric.
- Differentiating them is important so that behavioral problems that are caused by loss of cognitive functioning are not treated with anti-psychotic or anti-anxiety medications.
- Cognitive, or intellectual, symptoms are amnesia, aphasia, apraxia and agnosia (the 4 As of Alzheimer’s).
- Amnesia is defined as loss of memory, or the inability to remember facts or events. We have two types of memories: the short-term (recent, new) and long-term (remote, old) memories. Short-term memory is programmed in a part of the brain called the temporal lobe, while long-term memory is stored throughout extensive nerve cell networks in the temporal and parietal lobes. In Alzheimer’s disease, short-term memory storage is damaged first.

- Aphasia is the inability to communicate effectively. The loss of ability to speak and write is called expressive aphasia. An individual may forget words he has learned, and will have increasing difficulty with communication. With receptive aphasia, an individual may be unable to understand spoken or written words or may read and not understand a word of what is read. Sometimes an individual pretends to understand and even nods in agreement; this is to cover-up aphasia. Although individuals may not understand words and grammar, they may still understand non-verbal behavior, i.e., smiling.
- Apraxia is the inability to do pre-programmed motor tasks, or to perform activities of daily living such as brushing teeth and dressing. An individual may forget all motor skills learned during development. Sophisticated motor skills that require extensive learning, such as job-related skills, are the first functions that become impaired. More instinctive functions like chewing, swallowing and walking are lost in the last stages of the disease.
- Agnosia is an individual's inability to correctly interpret signals from their five senses. Individuals with Alzheimer's disease may not recognize familiar people and objects. A common yet often unrecognized agnosia is the inability to appropriately perceive visceral, or internal, information such as a full bladder or chest pain.
- Major psychiatric symptoms include personality changes, depression, hallucinations and delusions.
- Personality changes can become evident in the early stages of Alzheimer's disease. Signs include irritability, apathy, withdrawal and isolation.
- Individuals may show symptoms of depression at any stage of the disease. Depression is treatable, even in the latter stages of Alzheimer's disease.
- Psychotic symptoms include hallucinations and delusions, which usually occur in the middle stage. Hallucinations typically are auditory and/or visual, and sensory impairments, such as hearing loss or poor eyesight, tend to increase hallucinations in the elderly.
- Hallucinations and delusions can be very upsetting to the person with the disease. Common reactions are feelings of fear, anxiety and paranoia, as well as agitation, aggression and verbal outbursts.
- Individuals with psychiatric symptoms tend to exhibit more behavioral problems than those without these symptoms. It is important to recognize these symptoms so that appropriate medications can be prescribed and safety precautions can be taken.
- Psychotic symptoms can often be reduced through the carefully supervised use of medications. Talk to your primary care doctor, neurologist or geriatric psychiatrist about these symptoms because they are treatable.

Diagnosis

- Clinicians can now diagnose Alzheimer's disease with up to 90 percent accuracy. But it can only be confirmed by an autopsy, during which pathologists look for the disease's characteristic plaques and tangles in brain tissue.
- Clinicians diagnose "probable" Alzheimer's disease by taking a complete medical history and conducting lab tests, a physical exam, brain scans and neuropsychological tests that gauge memory, attention, language skills and problem-solving abilities.
- Proper diagnosis of Alzheimer's disease is critical since there are dozens of other causes of dementia that could exhibit the same symptoms. Some of these dementias, such as those caused by vitamin deficiency, thyroid problems and depression, are reversible; of those that are irreversible, Alzheimer's disease is the most common.
- The sooner an accurate diagnosis of "probable" Alzheimer's disease is made, the easier it is to manage symptoms and plan for the future.

Treatment

- Currently, there is no cure for Alzheimer's disease.
- Researchers are continually testing the effectiveness of various drug therapies that will control symptoms; slow, reduce and/or reverse mental and behavioral symptoms; and prevent or halt the disease.
- The U.S. Food and Drug Administration (FDA) has so far approved four drugs for the treatment of mild to moderate Alzheimer's disease. They are tacrine (Cognex®), introduced in 1993; donepezil hydrochloride (Aricept®), marketed since 1996; rivastigmine (Exelon®), available since the spring 2000; and galantamine hydrobromide (Razadyne™-formerly called Reminyl®), approved in February 2001. These drugs inhibit the enzyme that breaks down the brain chemical acetylcholine, and thereby may help slow the worsening of symptoms.

- The FDA in October 2003 approved memantine HCl (Namenda™) for the treatment of moderate to severe Alzheimer's disease, which can slow the decline in mental function.
- The National Institute on Aging, in concert with the FDA, tracks private- and government-sponsored clinical trials; contact the Alzheimer's Disease Education and Referral Center (www.alzheimers.org/trials or 800-438-4380).

Resource #11 – Alberta Health

Did a search for "Alzheimer's Disease." Top three hits are discussed below:

- 1 Healthy Aging in Alberta – Strategic directions. No information on Alzheimer's, is a strategic plan for the organization;
- 2 Another strategic plan for healthy aging in Alberta, but this document specifically about care for Alzheimer's and other similar conditions. No actual information on Alzheimer's disease;
- 3 A literature review of health services utilization of those 65 and over. No information on Alzheimer's disease.

Resource #14 – National Institutes of Health

Did a search for Alzheimer's Disease. One link under health topics, other links under publications. Top three are discussed below.

Site #1 – NIH Institute and Centre Resources. Clicked on Alzheimer's Disease under health topics. Took me to another page of links. Clicked on links (http://health.nih.gov/result.asp?disease_id=28&terms=Alzheimer's).

What are the Symptoms of AD?

AD begins slowly. At first, the only symptom may be mild forgetfulness, which can be confused with age-related memory change. Most people with mild forgetfulness do not have AD. In the early stage of AD, people may have trouble remembering recent events, activities, or the names of familiar people or things. They may not be able to solve simple math problems. Such difficulties may be a bother, but usually they are not serious enough to cause alarm.

However, as the disease goes on, symptoms are more easily noticed and become serious enough to cause people with AD or their family members to seek medical help. Forgetfulness begins to interfere with daily activities. People in the middle stages of AD may forget how to do simple tasks like brushing their teeth or combing their hair. They can no longer think clearly. They can fail to recognize familiar people and places. They begin to have problems speaking, understanding, reading, or writing. Later on, people with AD may become anxious or aggressive, or wander away from home. Eventually, patients need total care.

The Seven Warning Signs of Alzheimer's Disease

The purpose of this list is to alert the public to the early warning signs of one of the most devastating disorders affecting older people — Alzheimer's disease. If someone has several or even most of these symptoms, it does not mean they definitely have the disease. It does mean they should be thoroughly examined by a medical specialist trained in evaluating memory disorders, such as a neurologist or a psychiatrist, or by a comprehensive memory disorder clinic, with an entire team of expert knowledge about memory problems.

The seven warning signs of Alzheimer's disease are:

1. Asking the same question over and over again.
2. Repeating the same story, word for word, again and again.
3. Forgetting how to cook, or how to make repairs, or how to play cards — activities that were previously done with ease and regularity.
4. Losing one's ability to pay bills or balance one's checkbook.

5. Getting lost in familiar surroundings, or misplacing household objects.
6. Neglecting to bathe, or wearing the same clothes over and over again, while insisting that they have taken a bath or that their clothes are still clean.
7. Relying on someone else, such as a spouse, to make decisions or answer questions they previously would have handled themselves.

How is AD Diagnosed?

Today, the only definite way to diagnose AD is to find out whether there are plaques and tangles in brain tissue. To look at brain tissue, however, doctors must usually wait until they do an autopsy, which is an examination of the body done after a person dies. Therefore, doctors can only make a diagnosis of "possible" or "probable" AD while the person is still alive.

At specialized centers, doctors can diagnose AD correctly up to 90 percent of the time. Doctors use several tools to diagnose "probable" AD, including:

- questions about the person's general health, past medical problems, and ability to carry out daily activities;
- tests to measure memory, problem solving, attention, counting, and language;
- medical tests - such as tests of blood, urine, or spinal fluid; and
- brain scans.

Sometimes these test results help the doctor find other possible causes of the person's symptoms. For example, thyroid problems, drug reactions, depression, brain tumors, and blood vessel disease in the brain can cause AD-like symptoms. Some of these other conditions can be treated successfully.

What is the outlook for someone diagnosed with AD?

The course the disease takes and how fast changes occur vary from person to person. On average, AD patients live from 8 to 10 years after they are diagnosed, though the disease can last for as many as 20 years.

Why is early diagnosis important?

An early, accurate diagnosis of AD helps patients and their families plan for the future. It gives them time to discuss care options while the patient can still take part in making decisions. Early diagnosis also offers the best chance to treat the symptoms of the disease.

What drugs are currently available to treat AD?

No treatment can stop AD. However, for some people in the early and middle stages of the disease, the drugs tacrine (Cognex®), donepezil (Aricept®), rivastigmine (Exelon®), or galantamine (Razadyne®, formerly known as Reminyl®) may help prevent some symptoms from becoming worse for a limited time. Another drug, memantine (Namenda®), has been approved to treat moderate to severe AD, although it also is limited in its effects.

Also, some medicines may help control behavioral symptoms of AD such as sleeplessness, agitation, wandering, anxiety, and depression. Treating these symptoms often makes patients more comfortable and makes their care easier for caregivers.

What potential new treatments are being researched?

The National Institute on Aging (NIA), part of the National Institutes of Health (NIH), is the lead Federal agency for AD research. NIA-supported scientists are testing a number of drugs to see if they prevent AD, slow the disease, or help reduce symptoms. Some ideas that seem promising turn out to have little or no benefit when they are carefully studied in a clinical trial. Researchers undertake clinical trials to learn whether treatments that appear promising in observational and animal studies actually are safe and effective in people.

Mild Cognitive Impairment. During the past several years, scientists have focused on a type of memory change called mild cognitive impairment (MCI), which is different from both AD and normal age-related memory change. People with MCI have ongoing memory problems, but they do not have other losses such as confusion, attention problems, and difficulty with language. The NIA-funded Memory Impairment Study compared donepezil (Aricept), vitamin E, or placebo in participants with MCI to see whether the drugs might delay or prevent progression to AD. The study found that the group with MCI taking the drug donepezil were at reduced risk of progressing to AD for the first 18 months of a 3-year study when compared with their counterparts on placebo. The reduced risk of progressing from MCI to a diagnosis of AD among participants on donepezil disappeared after 18 months, and by

the end of the study, the probability of progressing to AD was the same in the two groups. Vitamin E had no effect at any time point in the study when compared with placebo.

Neuroimaging. Scientists are finding that damage to parts of the brain involved in memory, such as the hippocampus, can sometimes be seen on brain scans before symptoms of the disease occur. An NIA public-private partnership—the AD Neuroimaging Initiative (ADNI)—is a large study that will determine whether magnetic resonance imaging (MRI) and positron emission tomography (PET) scans, or other imaging or biological markers, can see early AD changes or measure disease progression. The project is designed to help speed clinical trials and find new ways to determine the effectiveness of treatments.

AD Genetics. The NIA is sponsoring the AD Genetics Study to learn more about risk factor genes for late onset AD. To participate in this study, families with two or more living siblings diagnosed with AD should contact the National Cell Repository for AD (NCRAD) toll-free at 1-800-526-2839. Information may also be requested through the study's website: <http://ncrad.iu.edu>.

Inflammation. There is evidence that inflammation in the brain may contribute to AD damage. Some studies have suggested that drugs such as nonsteroidal anti-inflammatory drugs (NSAIDs) might help slow the progression of AD, but clinical trials thus far have not demonstrated a benefit from these drugs. A clinical trial studying two of these drugs, rofecoxib (Vioxx) and naproxen (Aleve) showed that they did not delay the progression of AD in people who already have the disease. Another trial, testing whether the NSAIDs celecoxib (Celebrex) and naproxen could prevent AD in healthy older people at risk of the disease, has been suspended. However, investigators are continuing to follow the participants and are examining data regarding possible cardiovascular risk. Researchers are continuing to look for ways to test how other anti-inflammatory drugs might affect the development or progression of AD.

Antioxidants. Several years ago, a clinical trial showed that vitamin E slowed the progress of some consequences of AD by about 7 months. Additional studies are investigating whether antioxidants—vitamins E and C—can slow AD. Another clinical trial is examining whether vitamin E and/or selenium supplements can prevent AD or cognitive decline, and additional studies on other antioxidants are ongoing or being planned.

Ginkgo biloba. Early studies suggested that extracts from the leaves of the ginkgo biloba tree may be of some help in treating AD symptoms. There is no evidence yet that ginkgo biloba will cure or prevent AD, but scientists now are trying to find out in a clinical trial whether ginkgo biloba can delay cognitive decline or prevent dementia in older people.

Estrogen. Some studies have suggested that estrogen used by women to treat the symptoms of menopause also protects the brain. Experts also wondered whether using estrogen could reduce the risk of AD or slow the disease. Clinical trials to test estrogen, however, have not shown that estrogen can slow the progression of already diagnosed AD. And one study found that women over the age of 65 who used estrogen with a progestin were at greater risk of dementia, including AD, and that older women using only estrogen could also increase their chance of developing dementia.

Scientists believe that more research is needed to find out if estrogen may play some role in AD. They would like to know whether starting estrogen therapy around the time of menopause, rather than at age 65 or older, will protect memory or prevent AD.

Site #2 – This was a genetics fact sheet (<http://www.nia.nih.gov/Alzheimers/Publications/geneticsfs.htm>). Talks about how genetics may play a role in Alzheimer's Disease.

Site #3 – Is a question and answer page (<http://www.niehs.nih.gov/external/faq/aluminum.htm>). One question about if aluminium causes Alzheimer's. Is from the National Institute of Environmental Health Science.

Resource #15 – Google.ca

Did a search for Alzheimer's disease. There was one sponsored link; also, the user is offered information broken down by treatment, symptoms, etc.). Looked at top three sites.

Site #1 – Alzheimer's Association (<http://www.alz.org>). Clicked on warning signs (does not give symptoms), diagnosis, and treatment.

Some change in memory is normal as we grow older, but the symptoms of Alzheimer's disease are more than simple lapses in memory.

People with Alzheimer's experience difficulties communicating, learning, thinking and reasoning — problems severe enough to have an impact on an individual's work, social activities and family life.

The Alzheimer's Association has developed a checklist of common symptoms to help you recognize the difference between normal age-related memory changes and possible warning signs of Alzheimer's disease. There's no clear-cut line between normal changes and warning signs. It's always a good idea to check with a doctor if a person's level of function seems to be changing. The Alzheimer's Association believes that it is critical for people diagnosed with dementia and their families to receive information, care and support as early as possible.

10 warning signs of Alzheimer's:

1. Memory loss. Forgetting recently learned information is one of the most common early signs of dementia. A person begins to forget more often and is unable to recall the information later.
What's normal? Forgetting names or appointments occasionally.
2. Difficulty performing familiar tasks. People with dementia often find it hard to plan or complete everyday tasks. Individuals may lose track of the steps involved in preparing a meal, placing a telephone call or playing a game.
What's normal? Occasionally forgetting why you came into a room or what you planned to say.
3. Problems with language. People with Alzheimer's disease often forget simple words or substitute unusual words, making their speech or writing hard to understand. They may be unable to find the toothbrush, for example, and instead ask for "that thing for my mouth."
What's normal? Sometimes having trouble finding the right word.
4. Disorientation to time and place. People with Alzheimer's disease can become lost in their own neighborhood, forget where they are and how they got there, and not know how to get back home.
What's normal? Forgetting the day of the week or where you were going.
5. Poor or decreased judgment. Those with Alzheimer's may dress inappropriately, wearing several layers on a warm day or little clothing in the cold. They may show poor judgment, like giving away large sums of money to telemarketers.
What's normal? Making a questionable or debatable decision from time to time.
6. Problems with abstract thinking. Someone with Alzheimer's disease may have unusual difficulty performing complex mental tasks, like forgetting what numbers are for and how they should be used.
What's normal? Finding it challenging to balance a checkbook.
7. Misplacing things. A person with Alzheimer's disease may put things in unusual places: an iron in the freezer or a wristwatch in the sugar bowl.
What's normal? Misplacing keys or a wallet temporarily.
8. Changes in mood or behavior. Someone with Alzheimer's disease may show rapid mood swings – from calm to tears to anger – for no apparent reason.
What's normal? Occasionally feeling sad or moody.
9. Changes in personality. The personalities of people with dementia can change dramatically. They may become extremely confused, suspicious, fearful or dependent on a family member.
What's normal? People's personalities do change somewhat with age.
10. Loss of initiative. A person with Alzheimer's disease may become very passive, sitting in front of the TV for hours, sleeping more than usual or not wanting to do usual activities.
What's normal? Sometimes feeling weary of work or social obligations.

Diagnosis

A physician should be consulted about concerns with memory, thinking skills and changes in behavior. For people with dementia and their families, an early diagnosis has many advantages:

- time to make choices that maximize quality of life
- lessened anxieties about unknown problems
- a better chance of benefiting from treatment
- more time to plan for the future

It is also important for a physician to determine the cause of memory loss or other symptoms. Some dementia-like symptoms can be reversed if they are caused by treatable conditions, such as depression, drug interaction, thyroid problems, excess use of alcohol or certain vitamin deficiencies.

Currently, there is no cure for Alzheimer's. But drug and non-drug treatments may help with both cognitive and behavioral symptoms.

Researchers are looking for new treatments to alter the course of the disease and improve the quality of life for people with dementia.

In this section:

- Standard Prescriptions
- Behavioral Symptoms
- Alternative Treatments
- Talking with Your Physician

Here, can click on each type of treatment for more information.

Site #2 – National Institute of Aging under the National Institutes of Health. Is a fact sheet (<http://www.nia.nih.gov/Alzheimers/Publications/adfact.htm>).

What Are the Symptoms of AD?

AD begins slowly. At first, the only symptom may be mild forgetfulness, which can be confused with age-related memory change. Most people with mild forgetfulness do not have AD. In the early stage of AD, people may have trouble remembering recent events, activities, or the names of familiar people or things. They may not be able to solve simple math problems. Such difficulties may be a bother, but usually they are not serious enough to cause alarm.

However, as the disease goes on, symptoms are more easily noticed and become serious enough to cause people with AD or their family members to seek medical help. Forgetfulness begins to interfere with daily activities. People in the middle stages of AD may forget how to do simple tasks like brushing their teeth or combing their hair. They can no longer think clearly. They can fail to recognize familiar people and places. They begin to have problems speaking, understanding, reading, or writing. Later on, people with AD may become anxious or aggressive, or wander away from home. Eventually, patients need total care.

How is AD Diagnosed?

An early, accurate diagnosis of AD helps patients and their families plan for the future. It gives them time to discuss care while the patient can still take part in making decisions. Early diagnosis will also offer the best chance to treat the symptoms of the disease.

Today, the only definite way to diagnose AD is to find out whether there are plaques and tangles in brain tissue. To look at brain tissue, however, doctors usually must wait until they do an autopsy, which is an examination of the body done after a person dies. Therefore, doctors can only make a diagnosis of “possible” or “probable” AD while the person is still alive.

At specialized centers, doctors can diagnose AD correctly up to 90 percent of the time. Doctors use several tools to diagnose “probable” AD, including:

- questions about the person’s general health, past medical problems, and ability to carry out daily activities,
- tests of memory, problem solving, attention, counting, and language,

- medical tests—such as tests of blood, urine, or spinal fluid, and
- brain scans.

Sometimes these test results help the doctor find other possible causes of the person's symptoms. For example, thyroid problems, drug reactions, depression, brain tumors, and blood vessel disease in the brain can cause AD-like symptoms. Some of these other conditions can be treated successfully.

How is AD Treated?

AD is a slow disease, starting with mild memory problems and ending with severe brain damage. The course the disease takes and how fast changes occur vary from person to person. On average, AD patients live from 8 to 10 years after they are diagnosed, though some people may live with AD for as many as 20 years.

No treatment can stop AD. However, for some people in the early and middle stages of the disease, the drugs tacrine (Cognex, which is still available but no longer actively marketed by the manufacturer), donepezil (Aricept), rivastigmine (Exelon), or galantamine (Razadyne, previously known as Reminyl) may help prevent some symptoms from becoming worse for a limited time. Another drug, memantine (Namenda), has been approved to treat moderate to severe AD, although it also is limited in its effects. Also, some medicines may help control behavioral symptoms of AD such as sleeplessness, agitation, wandering, anxiety, and depression. Treating these symptoms often makes patients more comfortable and makes their care easier for caregivers.

New Areas of Research

The National Institute on Aging (NIA), part of the National Institutes of Health (NIH), is the lead Federal agency for AD research. NIA-supported scientists are testing a number of drugs to see if they prevent AD, slow the disease, or help reduce symptoms. Researchers undertake clinical trials to learn whether treatments that appear promising in observational and animal studies actually are safe and effective in people. Some ideas that seem promising turn out to have little or no benefit when they are carefully studied in a clinical trial.

Site #3 – MedlinePlus
(<http://www.nlm.nih.gov/medlineplus/alzheimersdisease.html>). Gave same information as the National Institute on Aging did above.

Resource #16 – Yahoo.com

Did a search for Alzheimer's disease. Hits number one and two were from the Alzheimer's Association and Medline Plus respectively. These were each reproduced above.

Site #3 – Alzheimer's Disease International (<http://www.alz.co.uk/>). Clicked on About Alzheimer's Disease, then clicked on the appropriate links.

Early symptoms

Every person is unique and dementia affects people differently - no two people will have symptoms that develop in exactly the same way. An individual's personality, general health and social situation are all important factors in determining the impact of dementia on him or her.

The most common early symptoms of dementia are:

Memory loss

Declining memory, especially short-term memory, is the most common early symptom of dementia. People with ordinary forgetfulness can still remember other facts associated with the thing they have forgotten. For example they may briefly forget their next-door neighbour's name but they still know the person they are talking to is their next-door neighbour. A person with dementia will not only forget their neighbour's name but also the context.

Difficulty performing familiar tasks

People with dementia often find it hard to complete everyday tasks that are so familiar we usually do not think about how to do them. A person with dementia may not know in what order to put clothes on or the steps for preparing a meal.

Problems with language

Occasionally everyone has trouble finding the right word but a person with dementia often forgets simple words or substitutes unusual words, making speech or writing hard to understand.

Disorientation to time and place

We sometimes forget the day of the week or where we are going but people with dementia can become lost in familiar places such as the road they live in, forget where they are or how they got there, and not know how to get back home. A person with dementia may also confuse night and day.

Poor or decreased judgement

People with dementia may dress inappropriately, wearing several layers of clothes on a warm day or very few on a cold day.

Problems with keeping track of things

A person with dementia may find it difficult to follow a conversation or keep up with paying their bills.

Misplacing things

Anyone can temporarily misplace his or her wallet or keys. A person with dementia may put things in unusual places such as an iron in the fridge or a wristwatch in the sugar bowl.

Changes in mood or behaviour

Everyone can become sad or moody from time to time. A person with dementia may become unusually emotional and experience rapid mood swings for no apparent reason. Alternatively a person with dementia may show less emotion than was usual previously.

Changes in personality

A person with dementia may seem different from his or her usual self in ways that are difficult to pinpoint. A person may become suspicious, irritable, depressed, apathetic or anxious and agitated especially in situations where memory problems are causing difficulties.

Loss of initiative

At times everyone can become tired of housework, business activities, or social obligations. However a person with dementia may become very passive, sitting in front of the television for hours, sleeping more than usual, or appear to lose interest in hobbies.

If you are experiencing any of these symptoms or are concerned about a friend or relative, visit your doctor and discuss your concerns.

Diagnosis

A reasonably accurate diagnosis of dementia can be made by taking a careful history of the person's problem from a close relative or friend, together with an examination of the person's physical and mental status. There is, however, no simple test to make a diagnosis and dementia can only be confirmed with certainty by examining the brain at post mortem. When making a diagnosis, it is important to exclude other treatable conditions that cause memory loss such as depression, urinary infection, vitamin deficiency and brain tumour. An early diagnosis is helpful, because it:

- enables caregivers to be better equipped to cope with the disease progression
- provides people with dementia with an opportunity to make decisions about their financial and legal affairs before they lose the ability to do so
- gives people with dementia a better chance to benefit from existing treatments.

Treatments

While there is no cure for Alzheimer's disease or for most other causes of dementia at present, many of the problems associated with dementia such as restlessness and depression can be treated. It may also be possible, especially in the early stages of dementia, to improve someone's memory with medication.

It is also possible to help people with dementia and their caregivers in a variety of practical ways. These include developing ways of caring for people with dementia which build on the strengths and abilities of those affected. This ensures that people with dementia maintain a sense of well-being and individuality throughout their illness.

Drug treatments

There is an immense amount of research taking place into new drug treatments for Alzheimer's disease and the other dementias.

Cholinesterase inhibitors

The main compounds used are the cholinesterase inhibitors (also known as anti-cholinesterase drugs). Four have been licensed for use in many countries. These drugs work by reducing the breakdown of acetylcholine in the brain. Acetylcholine is a chemical substance that occurs naturally in the brain and enables nerve cells in the brain to pass messages to each other. Research has shown that many people with Alzheimer's disease have a reduced amount of acetylcholine, and it is thought that the loss of this chemical interferes with memory function.

The cholinesterase inhibitors include donepezil (Aricept®), galantamine (Reminyl® or Razadyne®), and rivastigmine (Exelon®). An earlier drug of this type was tacrine (Cognex®), which has mostly been superseded by the newer compounds because of its significant side effects. Side effects of these drugs may include diarrhoea, nausea, insomnia or vivid dreams, fatigue and loss of appetite.

It is important to realise that these drugs are not a cure, and can only stabilise some of the symptoms of early to mid stage Alzheimer's disease for a limited period of time.

NMDA receptor antagonist

More recently, a different type of drug has become available, which works to modify the function of the NMDA receptor. This is involved with the chemical transmitter glutamate, and research has suggested that too much glutamate is damaging or toxic to the nerve cell. Memantine (known as Ebixa®, Axura® or Namenda®) has been licensed in several countries for treatment of moderate to severe Alzheimer's disease. It is the first drug for people in the later stages of the disease. Although memantine can help with the symptoms, there is no evidence that it modifies the underlying pathology of the disease.

Other drugs

A number of other treatments, including Vitamin E, oestrogen and anti-inflammatory drugs have shown some promising associations, but are not yet proven for routine use. Nootropics, such as Ginkgo Biloba, are available in many countries. Ginkgo seems to improve cerebral blood flow, but consistent improved outcomes with it have not yet been clinically demonstrated.

There is increasing evidence that diet and cholesterol may play a role in the development of the plaques which are characteristic of the pathology in Alzheimer's disease. Research is underway into the use of cholesterol lowering drugs, statins, in the treatment of Alzheimer's disease. Controlled trials of statins are assessing whether the rate of decline in Alzheimer's disease can be modified or slowed by these medications.

Other kinds of drugs are sometimes useful for controlling some of the symptoms of dementia, such as sleeplessness and agitation. In general, however, the use of drugs such as sleeping pills or tranquillisers should be kept to a minimum if someone has dementia, as they can cause increased confusion.

Resource #17 – MSN.com

Did a search for Alzheimer's Disease. The second and third links are from the Alzheimer Association and National Institute on Aging; both have been reproduced above.

Site #1 – Alzheimer Society
(<http://www.alzheimer.ca/english/disease/intro.htm>). Clicked on 10 warning signs, diagnosis, and treatment.

Ten Warning Signs

Alzheimer's disease is a progressive, degenerative disease. Symptoms include loss of memory, difficulty with day-to-day tasks, and changes in mood and behaviour. People may think these symptoms are part of normal aging but they aren't. It is important to see a doctor when you notice any of these symptoms as they may be due to other conditions such as depression, drug interactions or an infection. If the diagnosis is Alzheimer's disease, your local Alzheimer Society can help.

To help you know what warning signs to look for, the Alzheimer Society has developed the following list:

1. **Memory loss that affects day-to-day function**
It's normal to occasionally forget appointments, colleagues' names or a friend's phone number and remember them later. A person with Alzheimer's disease may forget things more often and not remember them later, especially things that have happened more recently.
2. **Difficulty performing familiar tasks**
Busy people can be so distracted from time to time that they may leave the carrots on the stove and only remember to serve them at the end of a meal. A person with Alzheimer's disease may have trouble with tasks that have been familiar to them all their lives, such as preparing a meal.
3. **Problems with language**
Everyone has trouble finding the right word sometimes, but a person with Alzheimer's disease may forget simple words or substitute words, making her sentences difficult to understand.
4. **Disorientation of time and place**
It's normal to forget the day of the week or your destination -- for a moment. But a person with Alzheimer's disease can become lost on their own street, not knowing how they got there or how to get home.
5. **Poor or decreased judgment**
People may sometimes put off going to a doctor if they have an infection, but eventually seek medical attention. A person with Alzheimer's disease may have decreased judgment, for example not recognizing a medical problem that needs attention or wearing heavy clothing on a hot day.
6. **Problems with abstract thinking**
From time to time, people may have difficulty with tasks that require abstract thinking, such as balancing a cheque book. Someone with Alzheimer's disease may have significant difficulties with such tasks, for example not recognizing what the numbers in the cheque book mean.
7. **Misplacing things**
Anyone can temporarily misplace a wallet or keys. A person with Alzheimer's disease may put things in inappropriate places: an iron in the freezer or a wristwatch in the sugar bowl.
8. **Changes in mood and behaviour**
Everyone becomes sad or moody from time to time. Someone with Alzheimer's disease can exhibit varied mood swings -- from calm to tears to anger -- for no apparent reason.
9. **Changes in personality**
People's personalities can change somewhat with age. But a person with Alzheimer's disease can become confused, suspicious or withdrawn. Changes may also include apathy, fearfulness or acting out of character.
10. **Loss of initiative**
It's normal to tire of housework, business activities or social obligations, but most people regain their initiative. A person with Alzheimer's disease may become very passive, and require cues and prompting to become involved.

Finding Out If It Is Alzheimer Disease

Alzheimer's disease is a progressive, degenerative disease. Symptoms include loss of memory, judgment and reasoning; difficulty with day-to-day tasks; and changes in communication abilities, mood and behaviour. If you notice any of these symptoms, it is important to see your doctor.

Why find out?

Symptoms of Alzheimer's disease can be similar to symptoms of other conditions such as depression, thyroid or heart disease, infections, drug interactions or alcohol abuse.

Finding out the cause of the symptoms can help people:

- understand the source of the symptoms
- get the proper care, treatment and support
- plan for the future

Making the diagnosis

There is currently no single test that can tell if a person has Alzheimer's disease. The diagnosis is made through a systematic assessment which eliminates other possible causes. Until the time when there is a conclusive test, doctors may continue to use the words "probable Alzheimer's disease." However, you should be aware that doctors making this diagnosis are accurate 80 to 90 per cent of the time.

Making the diagnosis can take time. The diagnosis can be made in a family doctor's office, a memory clinic or a hospital. The doctor may or may not feel that the person needs to see a number of health-care professionals to help make the diagnosis. These may include a psychologist, psychiatrist, neurologist, geriatrician, nurse, social worker or occupational therapist. They will look for problems with the person's memory, reasoning ability, language and judgment, and how these affect day-to-day function.

The process involves:

Medical history

Both the individual and family members or friends will be asked questions regarding the person's symptoms now and in the past. There will be questions about past illnesses and about family medical and psychiatric history.

Mental status exam

This part of the process tests the person's sense of time and place as well as the ability to remember, express herself and do simple calculations. It may involve exercises such as recalling words and objects, drawing and spelling, and questions such as "What year is it?"

Physical exam

To help rule out other causes, a physical exam will be done. The doctor will look for heart, lung, liver, kidney or thyroid problems that may be causing the symptoms. To evaluate whether other nervous system disorders are causing the symptoms, the doctor will test muscle tone and strength, co-ordination, eye movement, speech and sensation.

Laboratory tests

A number of tests will be done. Detailed blood work will be ordered to help detect problems such as anemia, diabetes, thyroid problems or infections that might be contributing to the symptoms.

Other tests such as X-rays and EEG's (electroencephalogram) may be used to determine the source of the problem. In some centres, scans may be used. The following may be recommended, but are not always necessary for a diagnosis:

CT (computerized tomography) scan and **MRI** (magnetic resonance imaging) take images of the brain.

SPECT (single proton emission computed tomo-graphy) shows how blood is circulating to the brain.

PET (positive electron tomography) shows how the different areas of the brain respond during certain activities such as reading and talking.

Psychiatric and psychological evaluations

A psychiatric evaluation may be helpful in ruling out other illnesses such as depression which can cause symptoms similar to Alzheimer's disease. Neuro-psychological testing can evaluate memory, reasoning, writing, etc.

Preparing for the assessment

On the day of the appointment, it will be useful to have the following information on hand. Writing this information down beforehand can be helpful.

Things you will be asked:

- What symptoms have been noticed?
- When did they first appear?
- How have the symptoms changed over time?
- What other medical conditions exist?
- What medications are currently being taken (both prescription and over-the-counter)?
- What herbal remedies and/or dietary supplements are currently being taken?
- Is there a family history of Alzheimer's disease or psychiatric conditions?

Things you may want to ask:

- Which tests will be performed? What is involved in the tests?
- How long will the tests take?
- How long will it take to learn the results?
- How are the results communicated? Who will be involved?

The family's role

Sometimes the person experiencing the problems will go to see her doctor. For others, the family will play a role in alerting the doctor of a problem.

Tips to lend a hand:

- Make the appointment for the person
- Help with transportation
- Share this brochure with other family members
- Offer to accompany the person to appointments and tests
- Help prepare information for the first appointment
- Appreciate that this can be an unsettling time for the person and provide emotional support
- Have patience; it can take a long period of time to arrive at a diagnosis

If the diagnosis is Alzheimer's disease

You may want to ask:

- What does the diagnosis mean?
- What can be expected over time?
- What care will be needed and is available, now and in the future?
- What treatment is available? What are the risks and benefits?
- What resources are available in the community to help?
- Are there any experimental drug trials to participate in?
- When is the next appointment?

Treatment

In this section, you can learn about drug treatments available in Canada, how new drugs are approved and find out about clinical trials and research studies.

[Drug Approval Process in Canada](#)

[Drug Treatments Available in Canada](#) (Ebixa®, Aricept™, Exelon™, Reminyl™)

[Alzheimer's Disease Clinical Trials and Research Studies](#)