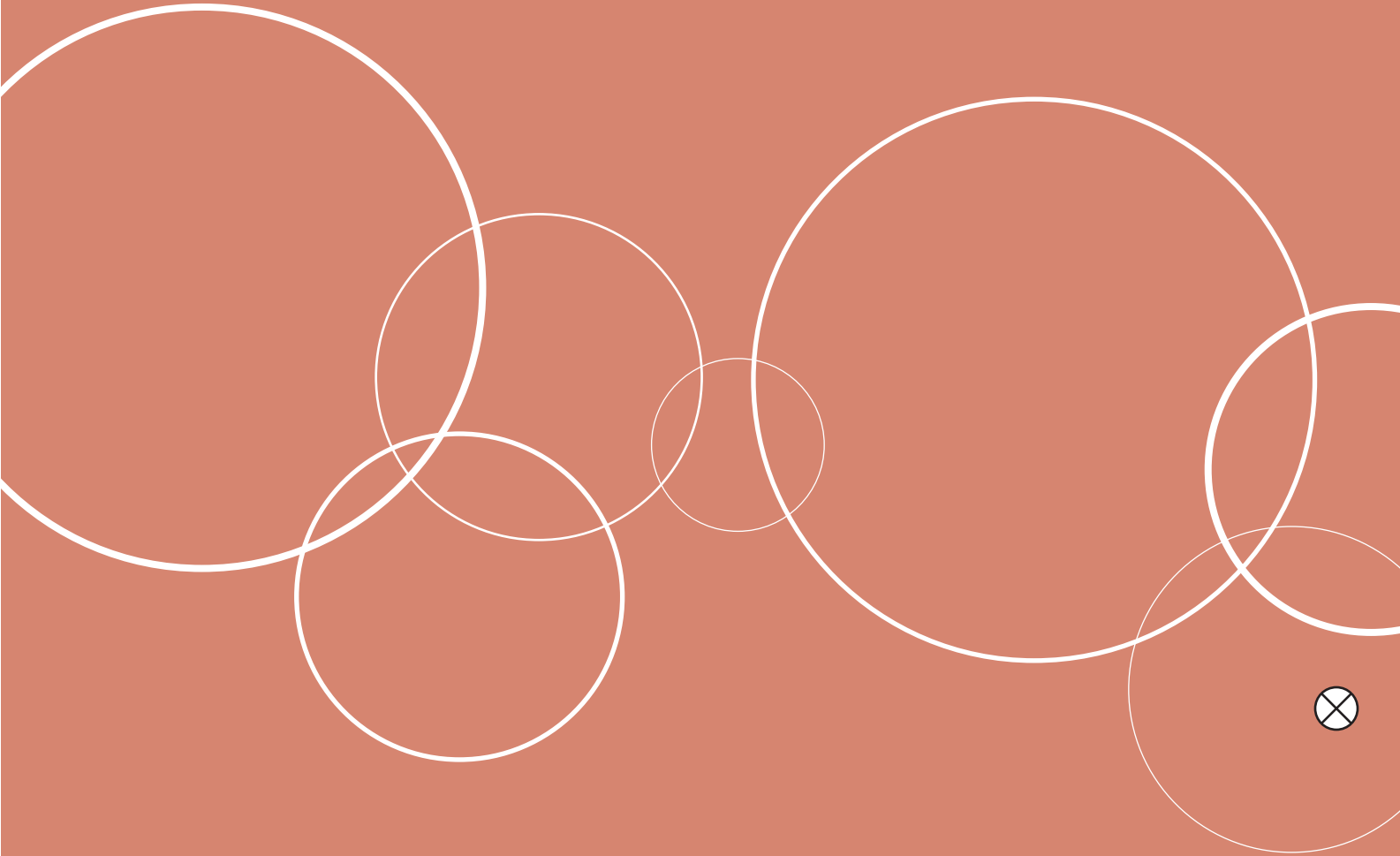




⊗ Living with Alzheimer's





Personal Health Organizer Contents

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Living with Alzheimer's

It may seem like information overload when trying to sort through everything you've read about Alzheimer's disease. This binder provides the necessary tools you need to sort through the many Alzheimer's resources you come across and keep track of only that which is relevant to you. Since no one experiences Alzheimer's in the exact same way, your binder can be organized in a way that best fits your needs. This binder is designed to help the person who has just been diagnosed, but many of the worksheets can be used together with family members or by caregivers of those who are in later stages of the disease.



THIS BINDER INCLUDES:

- Worksheets to help you plan
- Blank folders and tabs to help you organize
- Tips on finding help in your community
- A list of resources for more information



Worksheets, tabs and folders are provided following this booklet. Each booklet section explains the worksheets and how to use them. Use the included folders and tabs to keep the worksheets and all of your other information organized. While the worksheets can be photocopied, a CD with copies of the worksheets is also included in case you do not have access to a photocopier. By visiting www.agingresearch.org, you can download worksheets to your computer and also register your email address to receive worksheet additions and updates.

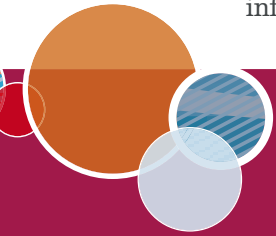
From the beginning, it is helpful to create a network of people that can help you relax and prepare for the future—whether they are family members, friends, or others in your community. Try to ask for help whenever you need it, and confide in those you feel comfortable with about your health and financial wishes. Reaching out to family members or friends that can help you organize this binder will ease the burden of organizing it by yourself.



General Information



The worksheets described in this section will help you organize information relevant to all sections of the binder. They can be used along with worksheets described in the other sections to keep track of tips that you find specifically helpful to you. The last section of this booklet has a list of resources available to help you find more information about all of the topics discussed, including information about local resources.



TO FIND HELP IN YOUR COMMUNITY, CONTACT:

- A university Alzheimer's research center near you
- Your local Alzheimer's Association chapter
(Visit www.alz.org/apps/findus.asp to find one near you)
- A local hospital—some have support groups and other resources
- A Community Health Department or Office on Aging

Binder Updates

The *Binder Updates* worksheet is designed to help you keep track of major updates to the binder. Use it in a way that is helpful to you, so you and your family know that the information included is up-to-date.

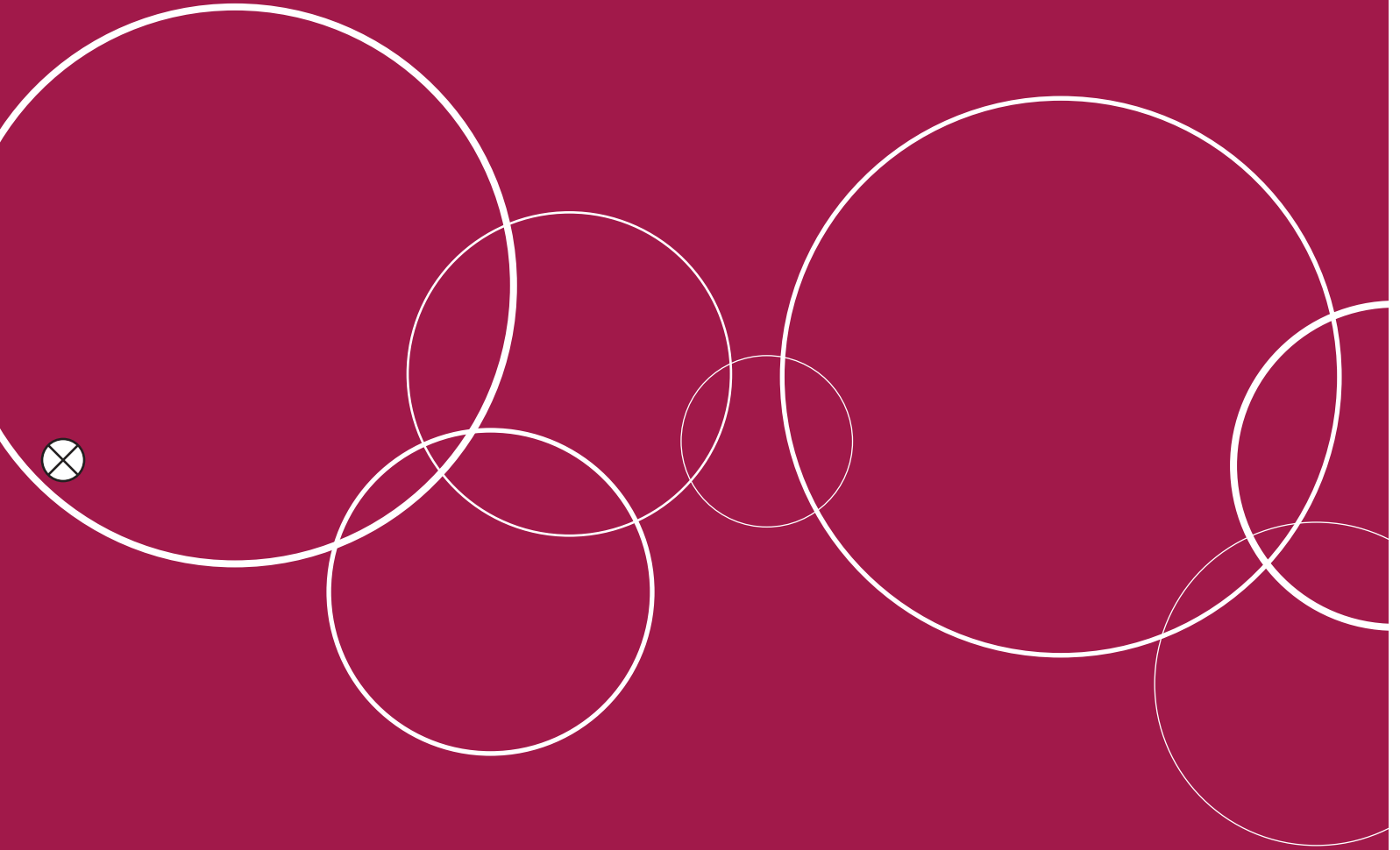
Important Contacts

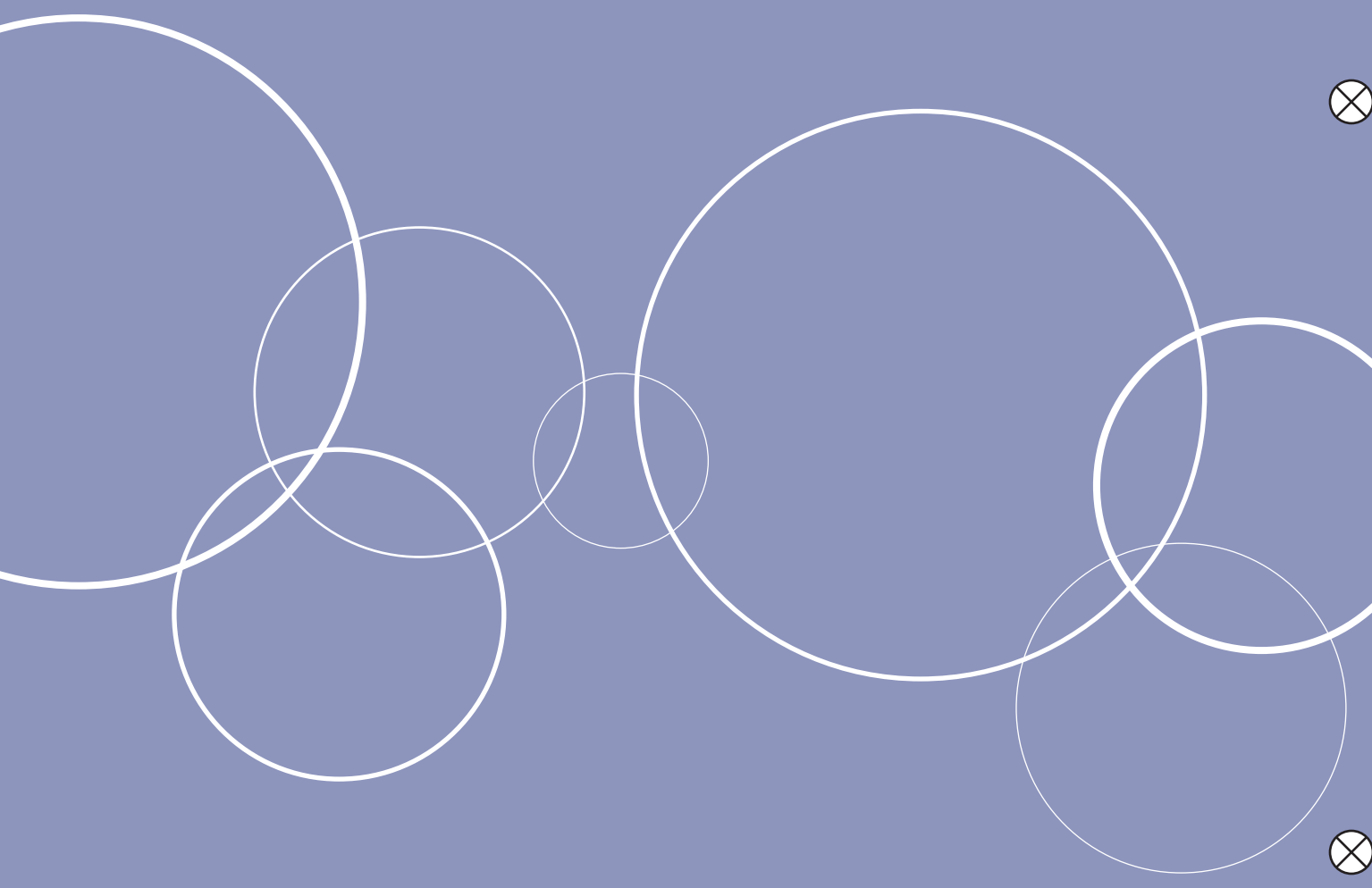
The *Important Contacts* worksheet will help you easily find important phone numbers and e-mail addresses. The "relationship to you" column is a place to record specifics such as a health care provider's specialty. In the "notes" section, keep track of other contact information such as website addresses. You may find it helpful to use a separate page for your family/friend, health and financial contacts.

Resource Notes

While reading about Alzheimer's and how to prepare, you may want to write down specific things that you find most helpful or relevant to you. The *Resource Notes* worksheet can help you organize these helpful tips, and it gives you a place to record where you found the information. This worksheet can be used both to keep track of books that have helped, or advice from family, friends or professionals.







*Keeping a positive outlook
and focusing on your health
after your diagnosis can help
you stay active longer.*

Staying Healthy

Keeping a positive outlook and maintaining your health can help you stay active and engaged in the activities you enjoy for many years. The worksheets described in this section will help you develop a health plan for yourself, and also record what you've accomplished. When creating your health goals, include a family member or friend—exercising is a lot more fun when you have a partner and will benefit both of you.

In addition to physical exercise, consider joining a support group in your community for individuals who are in the early stages of Alzheimer's disease. They can provide exactly what their name suggests—positive support from a group of people who know how you feel. This type of group can help your mental health.

TAKE ACTION:

- Learn a new skill
- Find an exercise partner
- Join a support group
- Attend a class at your local community center

My Alzheimer's Plan

The *My Alzheimer's Plan* worksheet will help you put your health plan in writing. Sections include:

- **Daily Reminders:** You may find it a little harder to remember things such as appointments and where you put your keys. Write down strategies that work best to help you remember.
- **Brain Activities:** These can include crossword puzzles, word searches, reading or playing an instrument.
- **Physical Activities:** It is recommended that adults get at least 30 minutes of exercise 5 days a week. Keep in mind that many daily activities, such as working in the garden or walking your dog, count towards your 30 minutes.
- **Staying Social:** Sometimes individuals who have just been diagnosed with Alzheimer's start to keep to themselves. Make a point to visit close family and friends and let them know that you would like to stay connected to them. Also, consider joining a class at your local community center or college.

Physical and Mental Exercise Log

After developing your plan, put it into action! The *Physical and Mental Exercise Log* will help you keep track of what you've accomplished, so you can make sure you're getting as much exercise as you need each day. In the notes section, record any positive or negative feelings you have while exercising. It is important to share any injuries or trouble you have while performing physical activities with your health care provider.

Food and Nutrition Log

The *Food and Nutrition Log* will help you remember what you've eaten each day, so you can make sure you're staying nutritionally healthy as well. Everyone finds it hard to eat a balanced diet daily even though it's important. A balanced diet helps to keep us emotionally and physically strong.

Visiting Health Care Providers

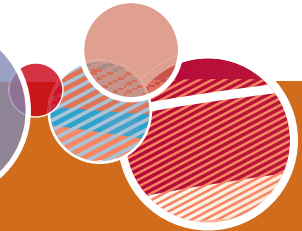


The worksheets in this section will help you better prepare for medical appointments. If you haven't found a health care provider or specialist yet, make sure you take your time when searching for one. Ask around—family and friends can be a great source for recommendations. There are also many online resources that can help you determine a certain provider's certification and you may even be able to find recommendations from current patients.

When looking for a provider, consider what is important to you in terms of care and treatment. Make sure you feel comfortable asking her/him questions and sharing your concerns. If you have multiple health care providers (such as a primary care physician and a neurologist that specializes in Alzheimer's disease), ask each of them if s/he will communicate with your other health care providers so your whole health care team knows the type of care you are receiving.

Sometimes insurance coverage can limit your choices. If your choice of health care providers is limited to a certain health care group/practice, you have the right to ask for a different provider within that group.

Communication is crucial when managing your overall health. It is important that your whole health care team knows about any treatments you are undergoing, side effects you may be experiencing, and any health concerns you may have. When you are meeting with a health care provider, don't hesitate to ask questions regarding your health, no matter how unimportant you think the question may be. Open communication between you and all of your health care providers will allow for better treatment results and less treatment complications.



THINGS TO LOOK FOR IN A HEALTH CARE PROVIDER:

- They are board-certified (meaning they have the minimum training needed for their specialty).
- They accept your insurance, if it is important to you.
- The services they provide fit your needs.
- They are available during emergencies (outside regular hours).
- You are comfortable with the way they listen and explain things.




Insurance Coverage for Health Procedures

It is important to make sure you know what to expect financially before any health procedure, whether it is a blood test or major surgery. Use the *Insurance Coverage for Health Procedures* worksheet to record exactly how much your insurance company covers. This will vary by procedure and the health care provider performing it. If you are concerned about the cost of a treatment or test, call your health care provider's office before your appointment and ask how much it will cost. Additionally, sometimes you cannot visit a specialist unless you receive pre-approval (most often called a referral) from your primary care physician. There is a place to record this on the worksheet.


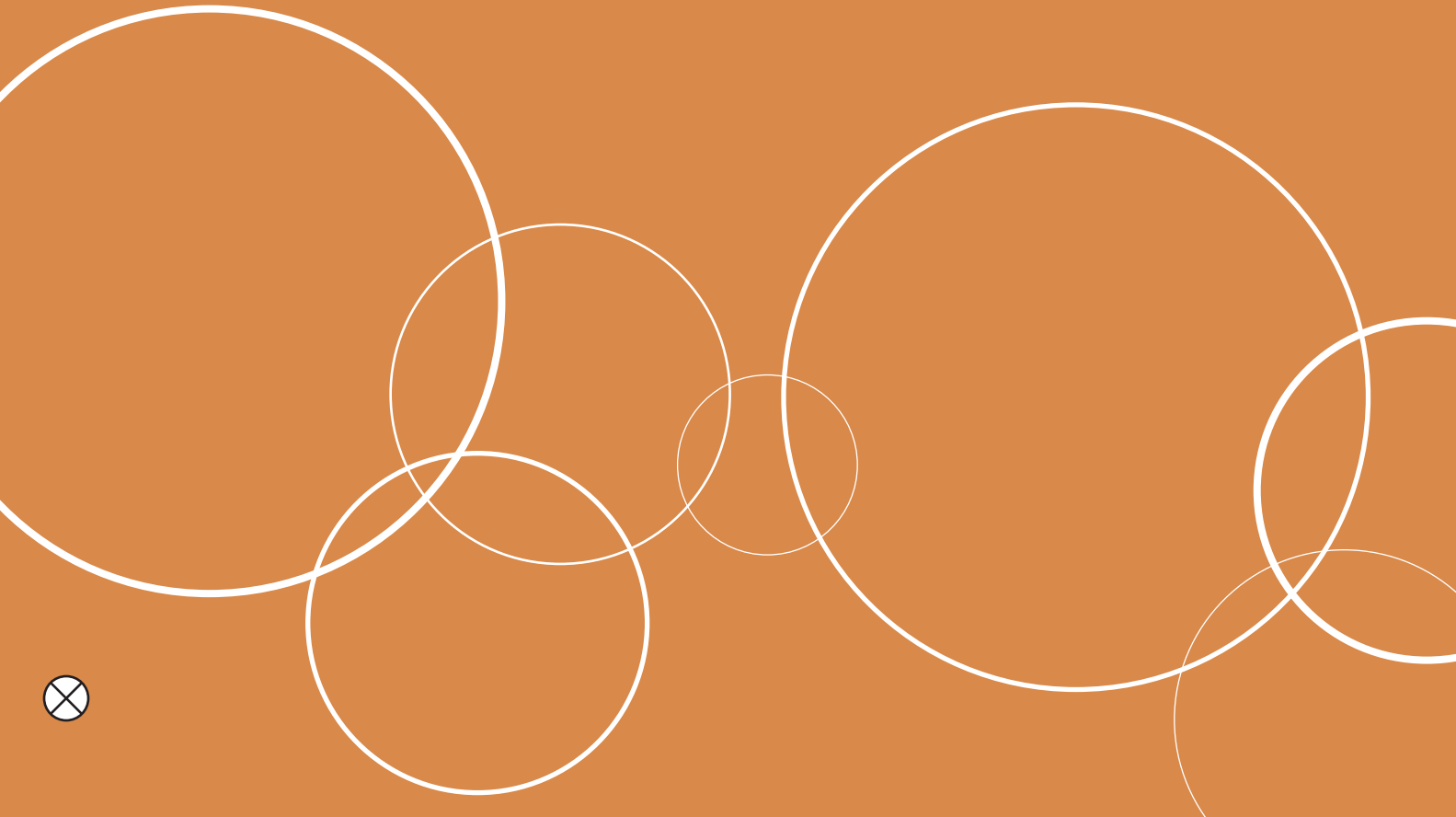

Health Appointment Form

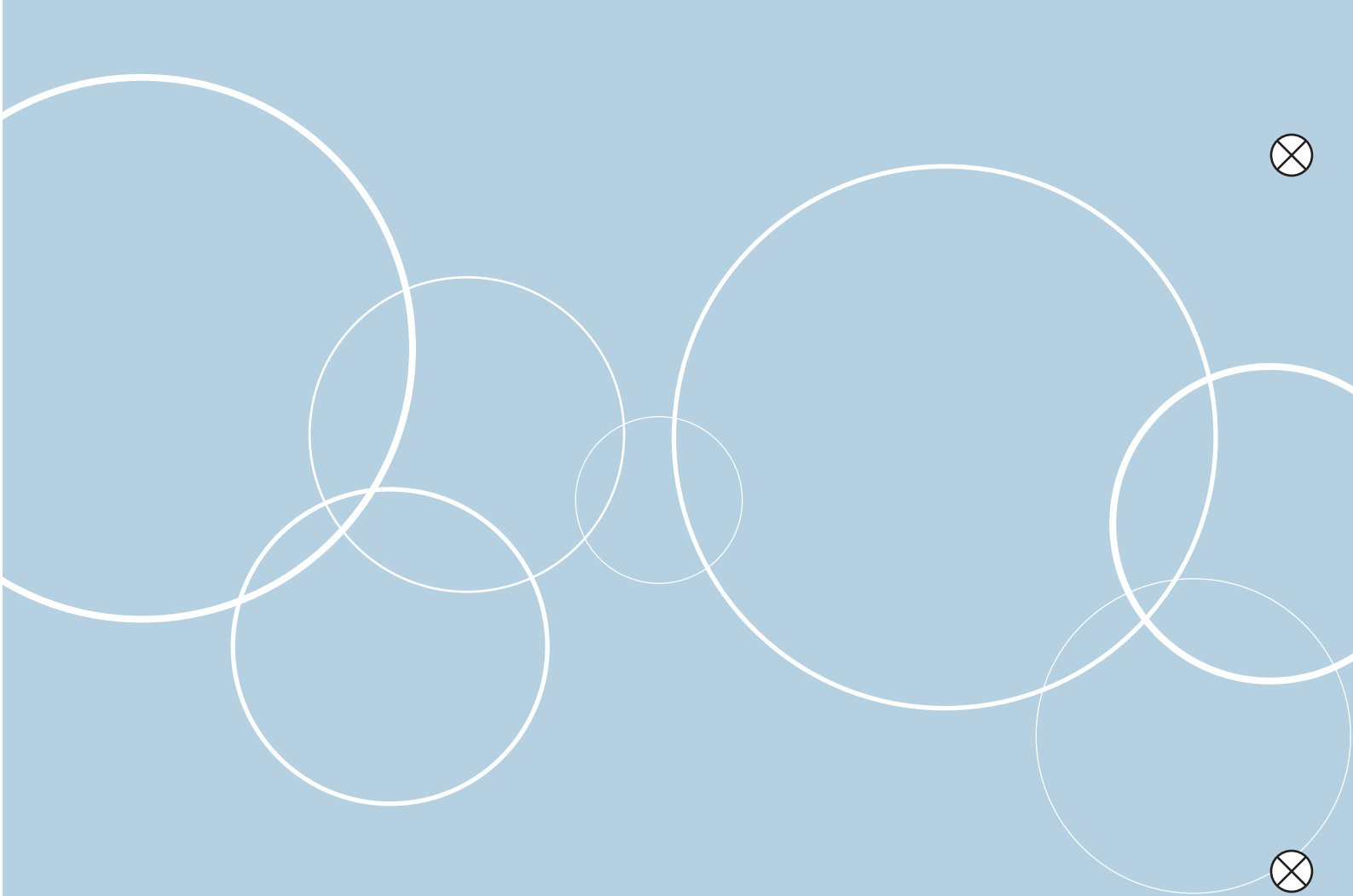
Preparing for appointments with your health care providers will help you make the most of your time. Use the *Health Appointment Form* worksheet to record the date and time of your appointment, and any questions you may have for your health care provider before the appointment. During the appointment, record any tests, diagnosis, or medication information that is discussed, as well as the answers to your questions. You can also keep track of the date and time of follow-up appointments. Consider having a family member or friend join you during medical appointments. There is so much to think about and two heads are better than one.





When looking for a provider, consider what is important to you in terms of care and treatment. Make sure you feel comfortable asking her/him questions and sharing your concerns.





*Keeping your own records will
improve communication between
you, your family and your entire
health care team.*

⊗ Keeping Health Records

It is a good idea for everyone, no matter their health status, to keep health records. Keeping your own records will improve communication between you, your family and your entire health care team. If you would like to review your medical history or change health care providers, it is convenient to have copies of your records that you can access easily. You don't need to sit down and fill them all out at once—ask a family member to help and only keep track of what is most useful to you.

Health Changes

Keeping a record of changes in your health can be a helpful resource for you and for those involved in your care. Use the *Health Changes* worksheet to record any changes in your physical health, mood or behavior. Your insights are valuable and can help your health care team determine whether a health change is caused by Alzheimer's or something else. Since people with Alzheimer's have varied symptoms, it is important for your health care team to know what time of day and how often your symptoms are occurring. Be sure to bring a copy of your *Health Changes* worksheet with you to medical appointments.

Personal and Family Medical History

⊗ You and your family's medical histories will provide insight into your risk factors for certain diseases and conditions. Ask family members for help when completing the *Family Medical History* worksheet, because your health may benefit from knowing these details. After gathering family information, fill out the *Personal Medical History* worksheet to help you keep track of diseases and conditions, health habits, surgeries and other hospitalizations that you have had. These are good worksheets to bring with you when you visit new health care providers so you can accurately fill out new patient paperwork. Update your personal information as your medical history changes.

Medication and Vaccination List

The *Medication and Vaccination List* should be used to record all over-the-counter and prescription medications you are taking, including any herbal supplements or vitamins. Bring this list to all health care appointments, and keep it up-to-date. This list will allow your health care team to know your overall treatment plan. Some symptoms you may experience could result from medication side effects or interactions. If you notice any health changes that happen at the same time your treatment has changed, record this on your *Health Changes* worksheet.

Use the vaccination section to record any vaccinations you have had, such as influenza (flu) or tetanus shots. This will help you remember when you received these vaccinations and when you are due for another one.

This worksheet also provides a place to record where you are currently keeping your medications. Try to store them all in the same location. If they have to be stored in more than one place, list each place on this worksheet. It is always important to keep your medications in a handy location, so you and your family members can quickly access them in an emergency situation.

Health Tests Taken

⊗ The *Health Tests Taken* worksheet will list, in detail, any health tests, surgeries or operations you have had. You can record the name of the test, type of test (such as memory, heart, vision, etc), health care provider that performed the test, results and if you had a follow-up appointment.

Finding a Clinical Trial

When new drugs are being developed, clinical trials are studies that determine their safety and effectiveness. If you are thinking about joining a clinical trial, the included worksheets provide important questions to ask. There are benefits and risks to every trial, so take the time to fully understand the pros and cons before you join. Your health care team can always help you with any other questions you may have.

COMMONLY USED TERMS:

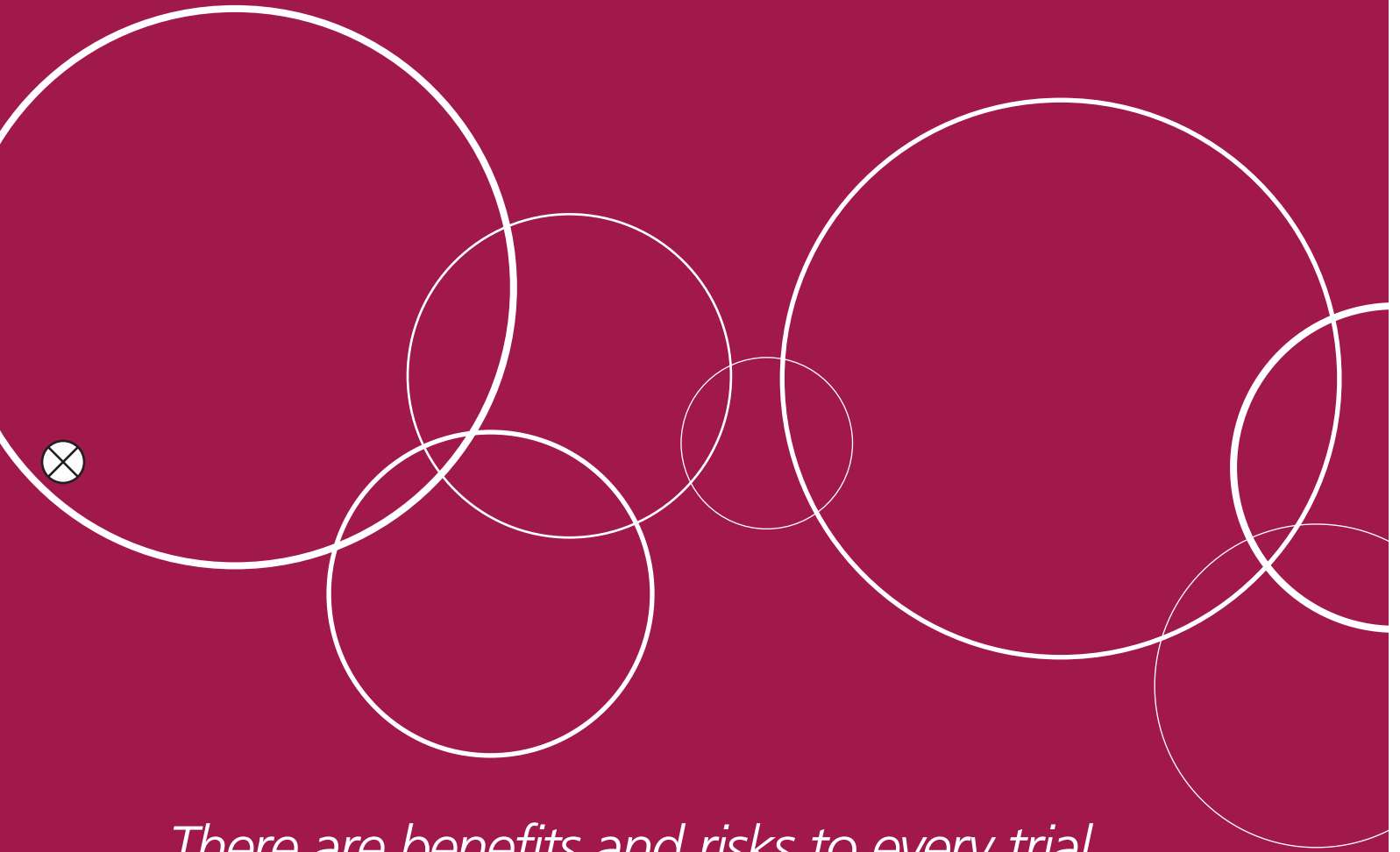
- **Phase:** Clinical trials are separated into 4 phases, depending on how much testing has been done on the treatment involved.
- **Placebo:** In some studies, there is a placebo, or substance that doesn't contain the treatment being tested. Participants in studies with a placebo do not know if they are getting the treatment or placebo. The placebo is used to make sure the treatment being studied actually works.
- **Eligibility Criteria:** Personal characteristics needed to participate in the study.
- **Invasive:** Procedures that involve entering the body, usually by cutting the skin or inserting instruments.
- **Debriefed:** Researcher(s) will tell you the full purpose of the experiment and the exact treatment(s) involved after the study.
- **Consent Form:** Participant signs this stating s/he is aware of the procedures, risks and benefits involved in the study; states that they are willing to participate.
- **Open-Label Study:** A study in which both the researchers and participants know the drug or treatment being given.

Clinical Trial Information

The *Clinical Trial Information* worksheet will help you initially sort through available clinical trials. Most information on this worksheet can be found in study descriptions online, but you may have to call for additional information.

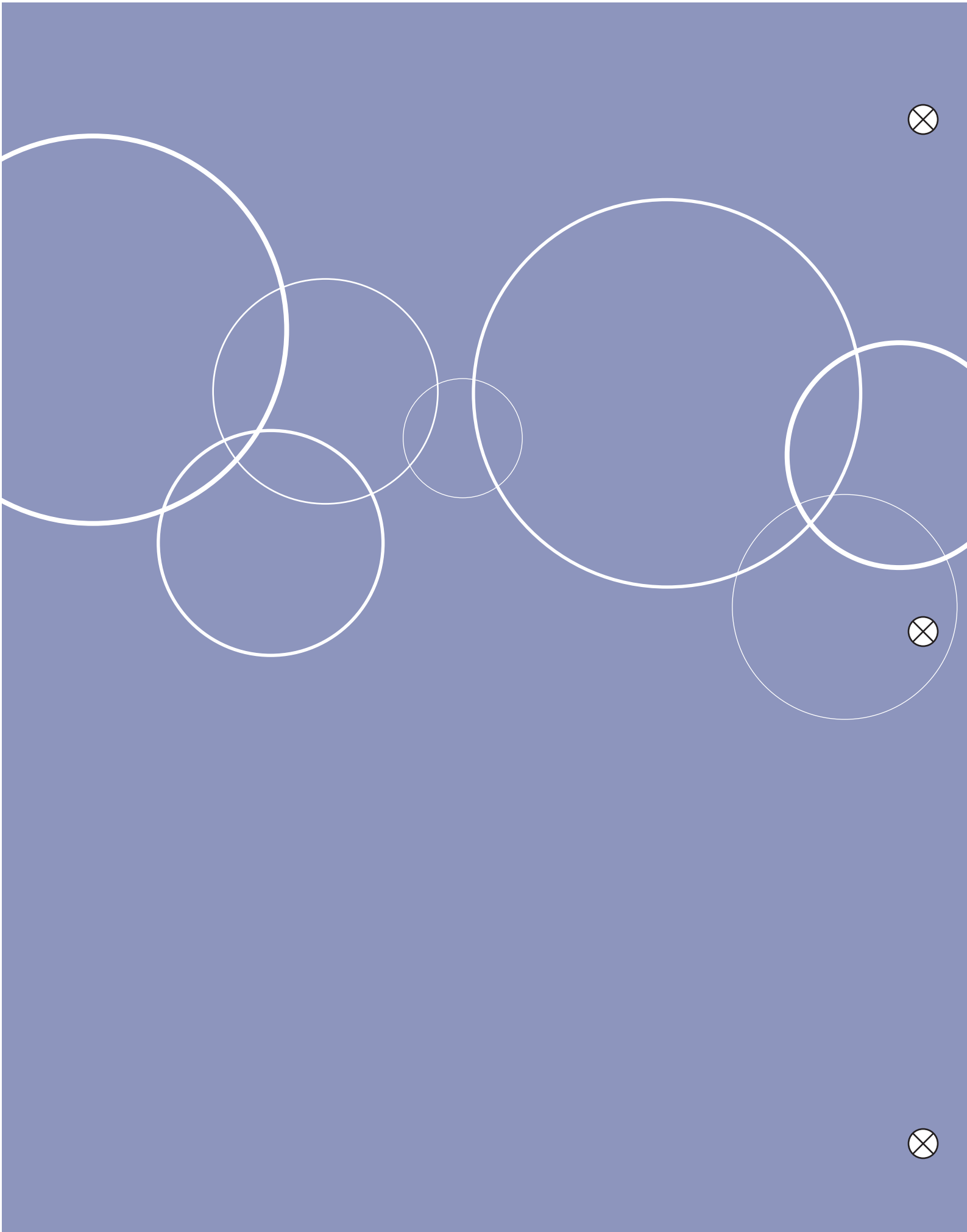
Clinical Trial Questions

After you find a clinical trial that you qualify for and interests you, there are additional questions you may want to think about asking the study's head researcher or physician. Use the *Clinical Trial Questions* worksheet to record answers to some of these questions. Feel free to add additional questions that you have. Make sure you feel comfortable with a study before you join.



*There are benefits and risks to every trial,
so take the time to fully understand the
pros and cons before you join.*





Organizing Other Key Details

Along with health records, there are other important documents that you need to consider creating. They will help your family know your wishes in the future when making financial and health decisions on your behalf. While you will probably go years without needing them, it is important to start thinking about them now.

If you decide to create documents, such as a living will, you may want to contact an eldercare attorney or financial advisor. An attorney can help you with documents such as a will, living trust, or durable powers of attorney. A financial advisor can help you with investment options, long-term care planning, and address tax issues.

Once you have gathered these documents, give copies to family members. Keep at least one copy of each form in this binder. All originals should be kept in a safe, fire-proof location, such as a fire-proof box at home or a bank safety deposit box.

DOCUMENTS YOU MAY WANT TO CREATE:

- **A Financial Durable Power of Attorney** identifies the person(s) who will make financial decisions for you if you are not able.
- **A Health Care Durable Power of Attorney** identifies the person(s) who will make health care decisions for you if you are not able.
- **A Living Will**, also known as an advance directive, states your wishes for end-of-life care. These wishes may also be listed in a Durable Power of Attorney for Health Care.
- **A Will or Living Trust** records your decisions for distributing your possessions and estate when you die.

Document Locations

Use the *Document Locations* worksheet to record where original copies of important documents are located and provide a family member with access information (a key, lock combination, etc).

Family Information

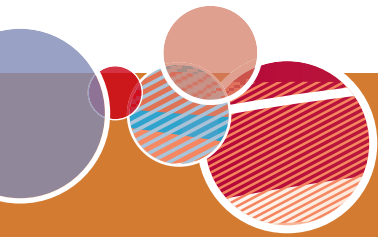
The *Family Information* worksheet can be used to record important information about your immediate family members. This will be helpful in an emergency.

Involving Family Members and Friends



When offering help, most people will not be specific. They may only offer a general, “Let me know if you need anything!” Creating a list of things you would like help with will enable people to give you what you really need.

Sometimes family members or friends become more distant. They may not know how to talk to you and may be afraid they will say or do something to hurt your feelings. You or a family member who understands the situation may have to be the one to initiate the conversation.



WHEN FAMILY AND FRIENDS OFFER TO HELP, YOU MIGHT ASK THEM TO:

- Organize this binder with you
- Go grocery shopping
- Help you find health care providers that fit your needs
- Exercise with you
- Help you with your monthly bills

Talking with Younger Children and Grandchildren

Children may not understand what you mean when you say you have Alzheimer’s, especially since they can’t see any physical changes. Ask them to be patient with you, and explain to them that you might be a little more forgetful than normal and may ask them to repeat things. There are books and other resources available for children about Alzheimer’s disease.



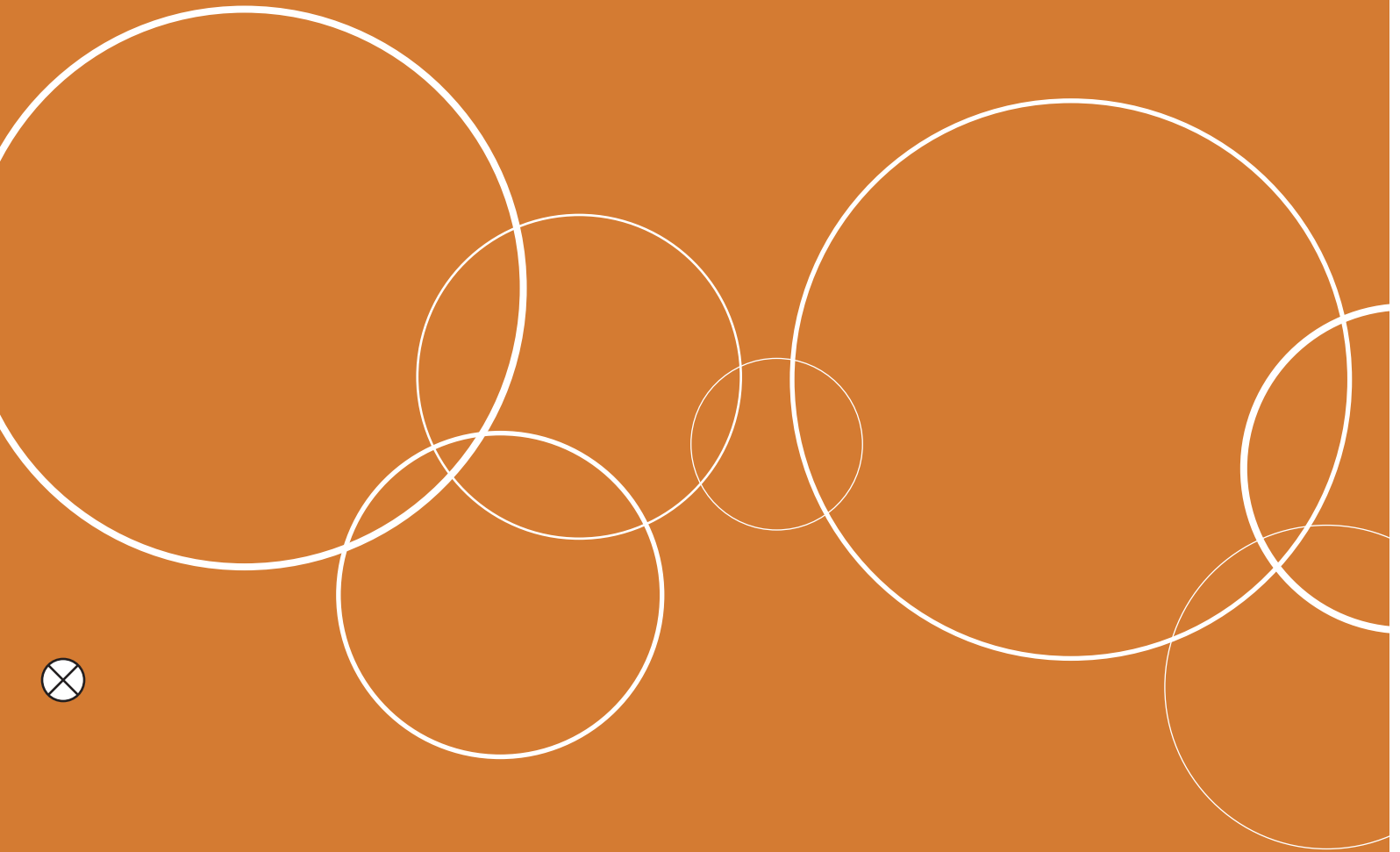
Talking with Older Family Members

When approaching family members, some may be in denial, while others may get frustrated, angry or simply not know what to do. Remind them that they should be angry at the disease and not at you or each other. It may be good to sit everyone down together and tell them how you feel. When talking with your family about your diagnosis:

- Be honest and tell them exactly what is difficult for you
- Tell them you need everyone’s support
- Make sure your wishes are heard
- Stress the importance of staying positive and laughing frequently

Something that may be fun for you and your family to do is put together a book of memories and stories that you have shared together. This could help spark laughter during an often frustrating time.





*Creating a list of things
you would like help with
will be useful when family
and friends offer to help.*



Resources

These resources can provide valuable information that will assist both you and your family. Information about support groups and tips on talking to your family can be found by visiting the organizations listed in the *General Alzheimer's Information* section.

General Alzheimer's Information

AARP

www.aarp.org/families/caregiving

Alliance for Aging Research

www.agingresearch.org

(202) 293-2856

Alzheimer's Association (National)

www.alz.org

(800) 272-3900

Alzheimer's Disease Education and Referral (ADEAR)

www.nia.nih.gov/Alzheimers

(800) 438-4380

A Quick Look at Alzheimer's, Four "Pocket" Films

www.aboutalz.org

Family Caregiver Alliance

www.caregiver.org

(800) 445-8106

Perspectives—A Newsletter for Individuals with Alzheimer's or a Related Disorder

University of California, San Diego, Shiley-Marcos Alzheimer's Disease Research Center, publisher. Available online free of charge by emailing request to lsnyder@ucsd.edu or calling (858) 622-5800.

U.S. Department of Health and Human Services

www.healthfinder.gov

Books

Alzheimer's Early Stages

By Daniel Kuhn, MSW
(Hunter House Publishers, 2003)

Speaking Our Minds—Personal Reflections from Individuals with Alzheimer's

By Lisa Snyder, MSW
(Health Professions Press, 2009)

The Alzheimer's Action Plan

By P. Murali Doraiswamy, MD, and Lisa P. Gwyther, MSW, with Tina Adler
(St. Martin's Press, 2008)

Clinical Trials

Alzheimer Research Forum

www.alzforum.org/dist/re/drcl/default.asp

Byrd Institute

www.byrdinstitute.org/clinic/trials.aspx

(866) 700-7773

CISCRP

www.searchclinicaltrials.org
(888) CISCRP3 (247-2773)

National Institutes of Health

www.clinicaltrials.gov

Community Resources

Agency on Aging

www.eldercare.gov
(800) 677-1116

Finding a Health Care Provider and Financial Assistance

America's Health Insurance Plans

www.healthdecisions.org

Benefits Check Up

www.benefitscheckup.org

Department of Veterans Affairs

www.va.gov

(800) 827-1000

Medicare

www.medicare.gov

(800) 633-4227

Medicare Rights Center

www.medicarights.org

(800) 333-4114

Revolution Health

www.revolutionhealth.com/doctors

Together Rx Access

www.TogetherRxAccess.com

(800) 250-2839

Financial and Other Future Planning

Aging with Dignity

www.agingwithdignity.org

(888) 594-7437

American Bar Association

www.abanet.org/elderly/toolkit/home.html

National Academy of Eldercare Law Attorneys

www.naela.com

Social Security Administration

www.ssa.gov

(800) 772-1213

Finding Care Facilities

Care Finder

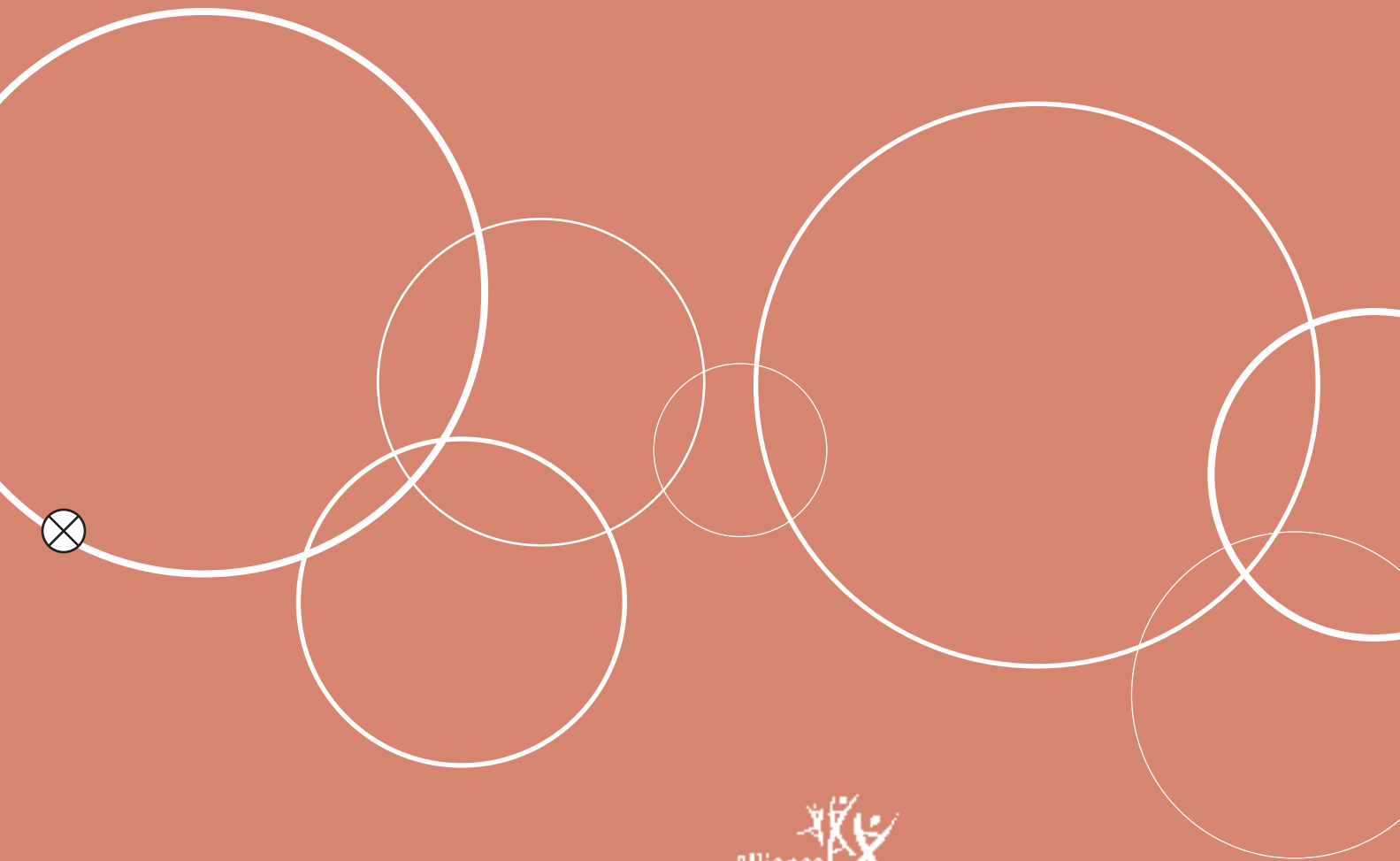
www.alz.org/carefinder/index.asp

(800) 272-3900

National Adult Day Services Association

www.nadsa.org

(877) 745-1440



The private, not-for-profit **Alliance for Aging Research** is the nation's leading citizen advocacy organization for improving the health and independence of Americans as they age.





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