

A GUIDEBOOK

# RESIDENTIAL OPTIONS



# FOR HAWAII'S SENIORS

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The Hawaii Association of Case Managers is a nonprofit professional association dedicated to providing education for the public and case managers, as well as promoting a high standard of practice in the profession.

We are pleased to provide this second edition of Residential Options for Seniors in Hawaii as a guide for understanding your many choices, and how to know what is right for your family. It also provides many resources for support as you navigate your way through this sometimes difficult passage in life.

Aloha,  
Sue Cornish, President

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# RESIDENTIAL OPTIONS

## FOR HAWAII'S SENIORS

### A GUIDEBOOK

In Hawaii our kupuna, our seniors, enjoy a beautiful climate all year around, fresh foods and an outdoor lifestyle. They are typically very healthy, and are often able to live independently, or with family in their homes. However, we must always plan for the possibility that the time may come when they are no longer able to receive adequate care and supervision at home.

It used to be that if an elder's health declined to the point where a family was not able to provide care at home, the only alternative for them was a move to a nursing home. Now there are more choices, less expensive alternatives and some innovative ways of preserving independence.

The time to have the conversation about care outside the home is *before* the need arises. Many seniors *want* to discuss with their families what will happen should they become unable to live independently, but find it is difficult to talk about.

Family members and friends may also find the subject to be emotionally upsetting as well as confusing. This may mean the decision is made in a crisis, such as during a hospitalization, resulting in fewer choices and even more emotional distress for everyone involved.

### GETTING STARTED

Careful planning is the key to making a successful decision regarding a change in a senior's residence and long term care. Do your homework, find out what resources are available to help you by contacting your Area Agency on Aging. These agencies each provide telephone hotlines and published directories for eldercare services in their local area.

On Oahu, call the Senior Hotline at 523-4545, and ask for the free Senior Information and Assistance Handbook.

If you are looking into residential options for yourself or another person, your first step is to carefully consider what care and help is required. Make a list of medical, physical and social needs. That includes:

### WHAT TO CONSIDER

## WHAT YOU NEED...

### What is actually required for daily care?

- Help with laundry, cooking, other household tasks;
- Help with walking, transferring, standing and sitting. Can you walk on your own, use a cane, walker, or a wheelchair?
- Help with eating, bathing and dressing, or going to the bathroom. Does this help need to be hands on, or simply someone standing nearby?
- Help with taking medications regularly: are reminders enough, or actually administering the meds?
- When is assistance needed: around the clock, during the daytime hours, or only at certain times of the day?
- Is there memory loss, confusion, or Alzheimer's disease?

## WHAT YOU WANT...

### What are the things you enjoy, that make life worth living?

- Would preference be to live in a home-like, community-based setting, or a larger facility offering a higher level of care?
- Is privacy important, or would one or more roommates be desirable?
- Would social contact with peers help avoid feeling isolated and depressed?
- Would preference be to participate in decisions about care, or to have these decisions made by other qualified individuals and/or professionals?

## WHO CAN HELP...

Identify your support network of family, friends and health care professionals—people who can help in various ways. Take this into consideration when choosing a residential setting. If the change is a possibility following a hospitalization, consult the discharge nurse or social worker *upon admission* to explore options. Don't wait until the last minute before the patient is discharged.

## CASE MANAGERS AND HOW THEY CAN HELP

A professional case manager, or geriatric care manager, is a good resource for many levels of help:

- **Assessment** – evaluating physical and mental condition, and recommending care options;
- **Arranging for Services** – a case manager can help to find the best residential option and assist with the actual move;
- **Monitoring and follow-up** – to be sure a person's needs are being met over an extended period of time;
- **Liaison** – or contact person, when family members live at a distance, or cannot keep in contact on a regular basis;
- **Advocate** – with health professionals, facilities, insurance companies, and others to ensure they receive maximum benefits;
- **Counseling and Support** – includes education about healthcare issues, conflict resolution and aging in general;
- **Other** – may include money management, guardian or conservatorship.

Most professional geriatric care managers have experience and special training in a field such as gerontology, social work, nursing or counseling. Many are members of professional associations and are certified or licensed in their field.

Before beginning to explore possible residential choices consider your financial situation, and what you can afford. Residential options for seniors vary greatly in cost, and it is important to keep an eye out for possible hidden costs.

## WHAT CAN YOU AFFORD?

COMMUNITY BASED CARE (see ARCH, ARCH-EC and Foster Care):

Community-based licensed residential care homes can range from \$1,200-\$6,500 per month. Prescriptions, medical and other supplies may be billed separately. Community-based care can be paid by Medicaid or SSI for individuals meeting the income and eligibility requirements.

ASSISTED LIVING:

Costs for assisted living vary according to the level of care and services provided. Some may require that you purchase your own unit, and pay a monthly maintenance fee. In Honolulu, assisted living is estimated to cost an average of \$39,000 per year.

## NURSING HOMES:

In Hawaii, long term care in a nursing home can cost between \$6,000-\$10,000 per month.

### HOW WILL YOU PAY?

At these rates, it's easy to see how personal income and assets can be used up rapidly. The three most common ways of paying for long-term care are:

- Direct payment by seniors and/or their families
- Medicaid / SSI
- Private long-term care insurance

One of the biggest mistakes many people make is assuming that government programs will pay for all of their long term care costs.

### MEDICARE

It is important to understand that federally financed Medicare coverage is primarily for acute stages of illness or injury and does not cover the needs of most people who may require an extended stay in a nursing home. It does not pay for custodial or long term care. Medicare wants you to "get well" and does reimburse for rehabilitative care. However, Medicare will cover some hospice benefits for medically certified individuals.

For more information on Medicare, call the Medicare Hotline (800) 633-4227, or SAGE PLUS, 586-7299.

### MEDICAID

Medicaid is a program designed to help people pay for certain health care services *who would not otherwise be able to afford them*. Many people confuse Medicare and Medicaid but the programs are very different.

Medicaid is based on financial eligibility standards, and requires an individual to "spend down" until their income and assets reach what is considered a poverty level. It covers nursing home costs and related medical expenses. The RACCP (Residential Alternatives for Community Care Program) is a Medicaid "waiver" program. It pays for long term care in a Foster Care Home or ARCH-EC.

Medicaid is financed jointly by the federal and state governments, and administered by the State Department of Human Services.

Call 587-3521, for information about Medicaid.

## **SOCIAL SECURITY (SSI)**

If an adult 65 or older and living in a state licensed care home cannot make their own payments, financial assistance may be available through the SSI (Supplemental Security Income) program of the Social Security Administration. Keep in mind that this is a very limited amount, and reduces the choice of residential settings.

Obtain information by calling SSI at (800) 772-1213.

## **LONG TERM CARE INSURANCE**

People are increasingly aware of how easily long-term care can wipe out a lifetime's savings. Purchasing a long term care insurance policy can be an excellent way to insure against the costs of long term care. Currently, consumers can choose among a wide variety of policy features, such as nursing home and/or in-home care, care by family or friends, care in assisted living facilities or care homes, hospice care. You can choose the daily benefit amounts and term of coverage.

Explore whether this option is right for you with a reputable agent, and compare quotes from several companies. Most importantly, choose an insurance company with a strong commitment to long term care coverage, highly rated, and preferably with no increases in premiums for in force policies.

Although this insurance is costly, the costs of long term care are also increasing. If you purchase a policy when you are relatively healthy, say in your 50s or 60s, you may be able to keep your premiums at an affordable level. Be sure to include an inflation protection provision.

Request a free copy of "A Shopper's Guide to Long-Term Care Insurance" from your insurance agent.

## **VETERANS BENEFITS**

If you are a military veteran you may be eligible for a wide range of benefits, including skilled or intermediate nursing care and related medical care in VA or private nursing homes.

Call the State of Hawaii Office of Veterans Services at 433-0420 or (800) 827-1000.

## RESIDENTIAL OPTIONS

### RETIREMENT OR SENIOR COMMUNITIES

RETIREMENT OR SENIOR COMMUNITIES provide residences for active and independent seniors within their own community. Some may require that you be over a certain age (usually 55 years) and may provide support services such as emergency call systems, dining facilities, housekeeping, transportation, and recreation and social programs.

Extra services are personally arranged for when required, so residents pay independently, and need not pay for services they don't use. Costs vary greatly between fee simple condominiums with additional maintenance fees, and government subsidized rental developments.

Call [Catholic Charities Housing Assistance Program at 595-0077](tel:595-0077) for information, counseling and referrals to affordable, possibly subsidized senior rental housing and assisted living facilities.

### ASSISTED LIVING

ASSISTED LIVING is a concept, as well as a specific type of residential option defined by Hawaii State laws. "Assisted Living" provides a range of services required to "age in place" in a homelike environment, and aims to maximize the dignity, privacy, and independence of the residents. Seniors live in their own private units. Emphasis is on an individual's right to make decisions about their own care and to accept responsibility for certain risks that may result from those decisions. Family and community involvement are encouraged.

Some assisted living facilities offer multiple levels of care so that you can enter requiring only a minimum of assistance, and stay by moving into an intermediate care facility on-site. This is called the "continuum of care" and they are also called "continuing care retirement communities."

An Assisted Living arrangement requires and provides a comprehensive assessment and care plan done prior to resident move-in. This serves as a baseline to determine the initial level of care, and the fee that will be charged. Then there will be an annual plan review by designated staff.

Services include:

- three meals daily with special dietary needs provided in a dining room or delivered to the resident's private apartment
- laundry and housekeeping
- transportation
- recreation and socializing
- personal care, such as assistance with bathing,

- dressing, eating, personal hygiene and walking;
- nursing assessment and health monitoring;
- emergency call buttons and special adaptations in apartments for access and safety;
- licensed, registered nurse available 24 hours a day, 7 days a week.

For information and a listing of licensed Assisted Living Facilities call the State Department of Health Office of Health Care Assurance at 692-7400, or online at [www.hawaii.gov/health/elder-care/health-assurance/licensing/index.html](http://www.hawaii.gov/health/elder-care/health-assurance/licensing/index.html)

The OAHU HOUSING GUIDE includes all major rental and retirement projects, as well as assisted living facilities on Oahu. See online at [www.elderlyaffairs.com/housingguide](http://www.elderlyaffairs.com/housingguide).

## OAHU HOUSING GUIDE

ADULT RESIDENTIAL CARE HOMES (ARCH) provide care and assistance in a home-like atmosphere, and are usually located in a residential neighborhood, although some of them are part of a larger facility. Rooms may be private or semi-private. They vary greatly in price, and may cost between \$1,200 - \$6,500 per month.

## ARCH

The time to consider moving into such a care home is when you are still fairly independent, but need some help and/or supervision.

Care homes are regulated and licensed by the State Department of Health Office of Health Care Assurance. The care home operator must be a specially trained CNA (Certified Nurse Assistant) with experience working in a hospital or a skilled nursing facility. Licenses are renewed each year with both scheduled and unannounced annual inspections.

Make sure that the care home has a current license, and that they allow you to review their inspection reports.

ADULT RESIDENTIAL CARE HOMES – EXPANDED CARE (ARCH-EC) Some Adult Residential Care Homes are licensed to provide a nursing home level of care for a limited number of their residents.

## ARCH-EC

For example, in a care home licensed for five residents, two may be “expanded care” which means they require more skilled and hands-on care, such as what they might receive in a nursing home.

Ideally, this enables residents of the ARCH to remain there when their level of care increases. The cost of care will also increase, and can be either private paid or Medicaid reimbursed for qualified individuals.

The “expanded care” of an ARCH-EC includes:

- more qualified staff and more strenuous training requirements;
- intermediate care (ICF) or skilled nursing (SNF) facility level care for a designated number of residents;
- services of a professionally licensed registered nurse or social worker to monitor clients’ care; and
- a registered nurse on call 24 hours a day.

For information or to locate an ARCH or ARCH-EC, call 692-7400, or access an updated list and vacancy report online at: <http://www.hawaii.gov/health/elder-care/health-assurance/licensing/vacancies.html>.

## **ADULT FOSTER CARE**

This is an option for those in need of nursing home level care. However, it is provided in a private home setting, and no more than two elder residents are cared for. As in other care homes, residents may choose to have a private or shared room.

The State of Hawaii Department of Human Services is the regulating agency, and a foster care home should have a current certification by the DHS. Care can be privately paid or reimbursed by the Residential Alternative for Community Care (RACCP) Medicaid waiver program.

The services of a case manager licensed by the Department of Human Services is required for all residents. Care must be provided by a Certified Nurse Assistant (CNA) with oversight by a registered nurse on call 24 hours a day. At present the base rate for Foster Care is \$3,000 - \$3,500 per month and includes room and board, case management and caregiving.

For information about foster care homes and the RACCP program call 586-5670, or go online to [www.state.hi.us/dhs](http://www.state.hi.us/dhs) and scroll down to Social Services Division/Adult Services, and find the list of licensed RACCP Case Managers.

A case manager is required for each resident of a Foster Home and expanded care residents of an ARCH-EC. Case managers are professionally licensed nurses or social workers, who provide assessment and care planning, monitoring of the client, and education of the caregivers to ensure quality of care. All residents have the right to have the case manager of their choice.

## NURSING HOMES

Skilled Nursing or Intermediate Care facilities, also known as “nursing homes,” provide professional level nursing services for seniors who have acute and/or chronic medical problems. Skilled nursing care may also be appropriate for someone who requires rehabilitative or extended care after a surgical procedure or other hospitalization.

Long term placement is available for those who have significant care needs and require monitoring of chronic medical problems. A doctor’s evaluation will be required for admission. Many times placement is made after a medical crisis when the hospital discharge worker must find one of very few available beds, and choice is diminished or eliminated entirely depending on vacancy. Become familiar with nursing homes you might feel comfortable with, by visiting a few ahead of time.

An excellent resource for evaluating different nursing homes and making the adjustment once you or your loved one has moved can be found at [www2.state.hi.us/eoa/programs/ombudsman/nursing\\_home\\_tips.html](http://www2.state.hi.us/eoa/programs/ombudsman/nursing_home_tips.html)

Nursing facilities are licensed and regulated by the State Department of Health. The Medicare website [www.medicare.gov/Nursing/Overview.asp](http://www.medicare.gov/Nursing/Overview.asp) has information that can help you to evaluate and compare nursing homes in Hawaii.

Memory Care is a relatively new concept that specializes in caring for people with Alzheimer’s disease or other types of dementia. Staff is often specially trained and skilled in handling the difficult behaviors, such as agitation or wandering, of people with memory loss and/or dementia.

Specialized programs and activities focus on the person’s strengths and consider their particular preferences and habits. Since persons with dementia have an even greater difficulty adapting to changes in their environment, memory care staff can help the resident and their family cope with moving and adjusting to their new home.

There are several memory care units within nursing homes or assisted living facilities, as well as a new model of freestanding care home which specializes in dementia care. There are also several respite care services providing memory care. Always inquire about special training and services which are offered in any residential or respite care service such as a care or foster home, or adult day program.

The Alzheimer’s Association , 591-2771, provides a list of their recommended residential and respite care options.

## MEMORY CARE

## RESPIRE SERVICES

Short term respite is a good option for people who are caring for an elderly person at home, and who may need a break for a few days, a week, or perhaps longer. Some caregivers find it helpful to use respite on a regular basis, for example, every weekend.

This can help them to balance their lives, spend time with their families, work or have needed personal time, so they can take care of themselves and be better caregivers.

Many care homes (ARCHes) and nursing homes offer this service for a daily or weekly fee. Care is provided by trained caregivers and usually includes oversight by a registered nurse or case manager. To locate respite care contact your Area Agency on Aging (see “Helpful Resources” on back cover).

## HOSPICE

Hospice provides a team of professionals to help people live as fully as possible, with comfort and relief from pain and symptoms, during their last months of life. Hospice care often can be provided wherever the patient is.

One of its great benefits is that it is usually provided in their own home, allowing the person to return to their most familiar and comforting environment. Hospice care is also available in some hospitals, nursing homes, expanded and foster care homes that have contracted with a hospice agency. There are also several freestanding residences which provide hospice care exclusively.

A physician can recommend hospice for someone who has no more than six months to live. The aim of hospice is to provide comfort, not a cure.

Hospice services include:

- Registered nurse on-call 24-hours/day to check medication, communicate with the doctor and train caregivers;
- Medical services by the person’s own physician and a hospice medical director, limited to pain relief and other comfort, or “palliative” care;
- Medical supplies and equipment;
- Home-care aides and volunteers for personal care, respite care, and other caregiver support;
- Assistance with benefit applications and documents such as advanced directives;
- Spiritual and grief counseling and support.

For information online go to [www.kokuamau.org](http://www.kokuamau.org), or contact these hospice organizations directly:

- Oahu: Hospice Hawaii, 924-9255  
[www.hospicehawaii.org](http://www.hospicehawaii.org)  
St. Francis Hospice, 595-7566  
[www.sfhs-hi.org](http://www.sfhs-hi.org)
- Big Island: Hospice of Kona, 334-0334  
Hospice of Hilo, 969-1733,  
[www.hospiceofhilo.org](http://www.hospiceofhilo.org)  
North Hawaii Hospice, 885-7547  
[www.northhawaii hospice.org](http://www.northhawaii hospice.org)
- Maui County: Hospice Maui, 244-5555,  
[www.hospicemaui.org](http://www.hospicemaui.org)  
Hospice Hawaii – Molokai, 553-4310
- Kauai: Kauai Hospice, 245-7277  
[www.kauai hospice.org](http://www.kauai hospice.org)

## MAKING THE DECISION

Now it's time to go back to your list of needs and desires, add your financial resources to the mix, and see which of the residential options you have just learned about may be a good solution.

You may want to consider moving while you are still relatively healthy and independent to take advantage of the new assisted living arrangements, rather than wait until you may not be eligible and must go an institutional type setting. Or, you may wish to remain at home as long as possible. Everyone is different, and what's important is finding out what is right for you.

One benefit of a long-term facility is its ready-made community of companions and helpers. However, residents rate personal contact with family and friends—by visits, phone, mail, and outings—at the top of their list of concerns. And, no matter how good a facility's own outreach programs are, a resident's ability to stay in touch with the larger community requires help from friends and relatives. Even when someone is living in a facility, they may still go out for social interaction at an adult day center, or other program they enjoy or is important to them as a part of their life.

### FAMILY AND FRIENDS

Whether family and friends are actively involved in a resident's life depends a great deal on whether the facility encourages their participation. Families should be regularly invited and encouraged to participate in activities with residents.

Together, the staff and family members should regularly review the resident's condition and care. Are there are procedures for family consultation about problems or changes in their care plan, room or roommate assignment? Ask whether there is an organized family support group.

### **MAKING THE MOVE**

The emotional stress of moving will be different for each person and their family. It helps to spend time planning and discussing the practical issues as well as how everyone is feeling.

It also helps very much if the elder is able to make their own decision, or is at least included in the planning. Having familiar people, surroundings and routines are very important to most elderly persons who are physically frail or mentally impaired.

Moving to a long term care facility can be so stressful that it can cause illness in some cases. Others may thrive because they are receiving better care and are relieved of burdensome tasks and worries they may have had prior to moving. Family members may feel guilty, or wonder if they made the "right decision." And, both the elder and their family may find that they are experiencing some grief for how things used to be, along with a sense of relief that the elder is safe and properly care for.

### **CHECK THE INSPECTION REPORT**

All licensed nursing homes, assisted living facilities and adult residential care homes are inspected regularly by the State Department of Health. Any violations of safety and care standards along with any resident complaints can be found in a written State Inspection Report or Compliance Survey.

These reports are public and copies should be posted and available for distribution. Even the best facilities will have some minor violations or complaints, but a report that mentions many serious health violations, or repeated neglect of residents, should raise a red flag. The administrator should be willing to discuss the report with you and to explain what they are doing to correct any problems.

Even a good report may not mean that everything is good when inspectors are not watching. When evaluating a facility, depend first and foremost on your own inspection.

Review the facility policy and contract, or agreement, completely. Take it home to discuss in detail, without feeling rushed. The agreement should spell out specific health care, personal care, equipment and supplies you will get for your regular daily, weekly or monthly fee. This should include frequency of nursing care, physical or other therapies, how emergencies are handled, number of meals and special dietary needs, transportation issues, and how medications are obtained.

The agreement should say whether, and how much, the regular rate will go up or down if the level of care is changed, whether the regular rate is guaranteed to remain the same for any length of time and how much notice must be given before rates are raised.

It is not uncommon for a resident of a long-term care facility to require hospitalization for some period of time, or perhaps to want to travel to visit family. Find out what the policy is on holding a resident's bed during their absence.

The Long Term Care Ombudsman program advocates for and protects the rights of residents of nursing and care homes. They respond to and investigate complaints and problems of residents or their families. To ensure quality of care, they also have trained volunteers who make unannounced visits to long term care facilities to observe and talk with the residents there.

On Oahu, phone 586-0100, or visit [www2.state.hi.us/ea/programs/ombudsman](http://www2.state.hi.us/ea/programs/ombudsman).

## WHAT TO LOOK FOR IN A WRITTEN AGREEMENT

## EVALUATION CHECKLIST

- Visit several different residential settings so that you can get a realistic idea of what they are like and how they compare.
- Always tour or visit at least once, and use all five senses when you are there:
  - What does the physical building and its surroundings look like?
  - What do you smell, how does it effect you?
  - Are there pleasant sounds, disturbing noises, or too much noise?
  - Visit during a mealtime, and see what is served; sample the food if possible. Do they provide for special diets?
  - How does the environment feel—peaceful, sad, anxious, cheerful, comforting?
- Talk with the caregivers. Are they comfortable answering your questions? Are they friendly and happy to be working there?
- Chat with the other residents and their visitors.
- Observe how staff interacts with residents and other family members.
- Are medical appointments arranged, and is transportation provided? How are the medications obtained, dispensed?
- Do they have meaningful activities, exercise, mental stimulation and learning, fun and laughter?
- Is there adequate staffing to meet the residents' needs? What help is there at night? Who provides the care when the care home operator is out? Is there a call bell system that is accessible?
- Do residents have choice in their daily life?
- What are the rules for visiting? Are visitors encouraged? Are unannounced visits allowed?
- Will they notify family promptly about changes in the condition of the resident?

**AREA AGENCIES ON AGING:**

**Elderly Affairs Division, City & County of Honolulu**

SENIOR HOTLINE, 523-4545

SENIOR INFORMATION AND ASSISTANCE HANDBOOK

[www.elderlyaffairs.com](http://www.elderlyaffairs.com)

**Kauai Agency on Elderly Affairs, (808) 241-4470**

**Hawaii County Office of Aging, (808) 961-8600**

**Maui County Office on Aging, (808) 270-7774**

**HELPFUL  
RESOURCES**

**Oahu Housing Guide, [www.elderlyaffairs.com/housingguide.html](http://www.elderlyaffairs.com/housingguide.html).**

**Catholic Charities Housing Assistance Program, 595-0077**

Information about senior rental housing

**State of Hawaii, Department of Health**

**Office of Health Care Assurance, 586-4080**

[www.hawaii.gov/health/elder-care/health-assurance/licensing/index.html](http://www.hawaii.gov/health/elder-care/health-assurance/licensing/index.html)

692-7400 for care homes, 692-7420 for nursing homes

**State of Hawaii, Department of Human Services**

586-5670 for information about Foster Care Homes

586-5541 for listing of RACCP case managers

**State of Hawaii, Executive Office on Aging**

[www2.state.hi.us/ea](http://www2.state.hi.us/ea)

**Long Term Care Ombudsman, 586-0100**

Neighbor Island 1-800-468-4644

[www2.state.hi.us/ea/programs/ombudsman](http://www2.state.hi.us/ea/programs/ombudsman)

**Medicare, [www.medicare.gov](http://www.medicare.gov)**

Hotline (800) 633-4227

**SagePlus, 586-7299**

Health insurance and Medicare counseling

Toll free 1-888-875-9229

**SSI, (800) 772-1213**

(Social Security–*Supplemental Security Income*)

**Medicaid 586-5390; Applications 587-3879**

**Veterans Affairs, Benefits Information (800) 827-1000**

**Alzheimer's Association Aloha Chapter, 591-2771**

Download a copy of this guidebook from the

**Hawaii Association of Case Managers website: [www.hacm.net](http://www.hacm.net)**

In Hawaii, our *kupuna* are typically very healthy. They enjoy a beautiful climate all year around, fresh foods and an outdoor lifestyle. We strive to help them live independently, or with family in their homes. The time may come when they are no longer able to receive adequate support and supervision in the home. If you have picked up this booklet, you may already be looking for some alternatives for yourself or a loved one.

It used to be that if an elder's health declined to the point where a family was not able to provide care at home, the only alternative for them was a nursing home. Now there are more choices, less expensive alternatives and some innovative ways of preserving independence.

The time to have the conversation about care outside the home is before the need arises. Surveys tell us that seniors *want* to discuss with their families what will happen should they become unable to live independently. Still, it can be difficult to talk about, and many families find the subject both upsetting and confusing. This may mean the decision is made in a crisis situation, resulting in less choice and more emotional distress for everyone.

This booklet is a map for understanding your choices and how to navigate this important decision-making process.

