

step three

creating a home

On a green island in Ontario
I learned about being human
built a house and found the woman
and we shall be there forever
building a house that is never finished

AL PURDY

george's story

Home alone too!

“MY WIFE AND I always expected that Rick would stay in our home. We thought perhaps the local community living association would take it over after we died, and turn it into a group home. Then Rick and others like him would live there.

“After attending a PLAN workshop on Letting Go, I began to wonder whether I was holding onto ideas that weren't in Rick's best interest. I had no idea if he would enjoy living with other people. I didn't know how he'd react to having staff supervising him. Well, actually I did know. Rick had lived in a group home years before and it hadn't worked out.

Maybe I'm being a little stubborn here, I thought. Maybe it would not be best for Rick after all.

“I thought I'd better take this up with Rick. He didn't think too much of the idea at first. Then all of a sudden it was decided. Rick would move. Rick and his Personal Network decided, that is, not me. It was quite a shock.”

Their neighbour across the street who had been invited to the first meeting knew of a vacancy in an apartment building that was centrally located. So Rick moved out. “It's a start,” says George. “The apartment's his home now—he doesn't have his old man there to bother him.”

“Fortunately there have been no big problems. He took it in his stride. Actually he has matured quite a bit as a result of the move. He likes to boast that he knows all 15 people in

the building and they all talk to him. What a difference from his old neighbourhood where so many of the people he knew had moved away. And I must admit I like the idea that he is surrounded by people who accept him and, in their own ways, check up on him.”

And there's more. Rick has just found a two-bedroom apartment in the same building. Bob, his friend since childhood, is moving in with him. George suspects Rick has at least one more move ahead of him and that it will be into a place he owns himself, or at least a home that Rick's discretionary trust owns on his behalf. ■

step three

Creating a home

Only when
you discover
yourself can
you be secure.

DAPHNE ODJIG

A home of one's own. This is the universal dream, occupying a powerful place in our individual and collective psyche. Home as haven and home as hospitality convey the intangible aspects of home. Home as feeling—the feeling you get when at the end of a long day you open your front door and exhale, Ah, I'm home.

In Al Etmanski's book, *A Good Life*, he writes about the essence of home having nothing to do with wood, nails, bricks, and mortar. Rather, it's about sweat and laughter, bruises and tears, stains and cobwebs, flowers and slammed doors, failures and promises, kisses and fingerprints. Home is where we can just be, where we become, where we belong. Home is not a program or a service; it is your sanctuary.

The word "home" comes from a Sanskrit root meaning a safe place to lie down; a separation of outside from inside, defined by a threshold.

Isn't that the kind of place we want for our friends and family members with disabilities? A place that provides continuity and security? A place that ensures privacy and reflects the personality of those who live there?

Making a house a home

Parents the world over rank a stable and hospitable living environment as a high priority for their sons and daughters. A house, however, doesn't become a home by accident. It requires thoughtfulness and care. It starts by understanding the meaning of home to your relative. What are they used to? How can you recreate that? How do you guarantee that a heap of living will take place there? See Worksheets 6 and 7 at the end of this step to help answer these questions.

The wisdom of mothers

THE WILL WAS CLEAR: sell my house. The executor was only following the instructions of Garland, David's mother. The home David had lived in for 28 years was to be sold. For a man who relied on order and predictability this could have been a disaster.

What was his mother thinking?

In fact she knew what she was doing. She was house rich and cash poor. All her money was tied up in her home. She needed to liquidate in order to finance David's trust and his financial security.

Besides, she, PLAN Vancouver, and David's Network had prepared for this time for two years.

Network Members helped David find his new place, an apartment in a stately old home, right on the bus line. They borrowed a truck and helped him move. They built bookcases for his opera and classic movies video collection. They hung new curtains. Even the trust officer got into the act, collecting all the family photographs and placing them into the albums with David.

But the unthinkable did happen. On his first weekend in his new place David got locked out. He couldn't get in the main door. He tried and tried, becoming more and more frustrated. We imagined his mother must be turning in her grave.

Eventually David crossed the street to a phone booth and called one of his network members. No answer so he called another. John was home but lived on the North Shore—too far to get there quickly. John did, however, arrange for another Network Member to come right over. Unable to make the keys work either, he invited

David to spend the night at his home. The next morning they returned, spoke with the landlady who, it turns out, was the one who changed the lock. Turns out, David was not the only one having trouble.

David's mother had decided to rely on PLAN so she became a Lifetime Member. She realized she had no other choice since she was the last surviving family member.

She asked PLAN to provide advice to her trustee on expenditure from the trust and to keep David's network strong and vibrant.

Engaging three members of David's network after midnight and on a weekend isn't something she predicted but it is something she expected. ■

If mealtime is a renewable resource, then food is a social lubricant that can keep the machinery of involvement and interaction running between people with and without disabilities.

KAREN MELBERG SCHWIER
AND
ERIN SCHWIER STEWART

Some of our sons and daughters will want to have their own place. They'll want to live on their own or with people they know and like. They'll need very little staff support. Others will need intensive staff support.

Once this sense of home has been clarified, you can examine the type of tenure and other technical details that best suit your relative, and perhaps your pocket book! For example, at the end of this chapter—in Jackie's story—we will describe how the assets in an RDSP can be used to purchase a home.

Home can exist wherever you live and regardless of who owns or manages the building, house, apartment or room. The key to creating a home is to have control over the home environment; to make sure it reflects your family member's personality; to ensure that your family member chooses their own roommates. One of our past Presidents is very satisfied with the group home her son lives in and we have to say we agree with her. Every time she visits Peter, there is laughter—surely one of the languages of home. Mind you, she is a respected advocate, who is on top of everything. She has briefed and prepared Peter's Personal Network to carry on her vigilance.

Regardless of where our relatives live, we want them to have choice; in other words, we want our relatives to live in a place that respects their choices; a place where their personality shines through.

Many of us cannot afford to assist our family members in purchasing their own home. We're still paying down our own mortgages. There are alternatives to private home ownership, however, that will provide long-term stability. Housing cooperatives and land trusts, for example, have many of the advantages of home ownership. So does home sharing; that is, living with others who do not have a disability. If these options are not available or appropriate, we suggest you consider rental.

Rental accommodation—particularly rent to own—can allow people to establish a sense of their own place and to maintain control of their living environment. It may not be for everyone but being a tenant provides your relative with the flexibility to try different living arrangements, particularly when they are starting out and first leave home.

beth's story

Beth's dream... in shades of pink!

LIKE MANY PARENTS of children living with disabilities, Roz and Lynne Vincent-Haven always wanted Beth to have a good life—for them, this meant opportunities for choice in a safe environment. They had some vague vision that perhaps by the time Beth was 30 she'd be able to live away from home, semi-independently, and in a community.

When Beth was 25 years old, she attended a PATH (Planning Alternative Tomorrows with Hope) day. When the facilitator met with Beth a few days before, they asked her what she needed to be sure it was included in the PATH. She very clearly responded, "Moving... moving out!" This was Beth's second PATH and she was excited to have the opportunity to explore a new dream. Until that time, Beth's family had no idea that she was even thinking about—let alone wanting to plan—leaving home!

On PATH day—with the 11 friends that made up Beth's network included—the team focused on Beth's dream of moving out. Beth directed this process. She described exactly where she wanted to live and what kind of amenities had to be included: It had to be a high-rise apartment with an elevator and stairs for safety. She wanted her own bedroom but could share a bathroom if needed. She wanted to live with friends—but not a boy friend—and the building

needed a pool, an exercise room, and a party room. This dream building would be close to a bus stop and, of course, for those who know Beth, the apartment would have to be painted pink!

Over the next 18 months, Beth set out to learn all the skills she'd need to make the move to independent living a successful one. She started doing her own laundry, she cooked more using the stove and the microwave, and she began learning how to clean her own personal space.

During this time Beth also signed up for a program called Trying It On For Size, run by a local community living group that helps individuals learn to live independently in an apartment with support.

Beth's network was also a big help, taking her out to look at various types of apartments. They also gave her presents for her hope chest, things she'd need once she moved out.

Even though things were moving forward, they weren't working fast enough for Beth. The once exuberant young woman had become withdrawn and sad. Roz and Lynne wondered if Beth was having second thoughts about moving out. For support, the family turned to Sue, Beth's facilitator from the Foundations

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I prefer grace to miracles.

DAVID ROCHE

We see no reason why people who live in group homes and who need staff support for their personal care should be denied the benefits of living in a home-like setting. This may not be easy. Not every agency appreciates the difference between house and home. You may have to search for the right agency. You may have to advocate. You may have to change your relationship with the current service provider.

These options are more feasible now. The existence of microboards and the promotion of individualized planning and funding demonstrate a respect for the individual's wishes and a commitment to personalized, customized supports rather than catering to the needs of the group.

Limitations of current housing options

Governments spend millions of dollars every year on housing for people with disabilities. That's a good thing. The challenge for advocates and parents alike is to ensure that control of the home environment doesn't rest exclusively with the agency or service provider. The progressive agencies out there today are responsive and sensitive to making genuine homes out of their group living arrangements. But families still worry. What if there is a change in staff, the home supervisor, or in agency leadership? What will happen if there are funding cutbacks?

It's not that group homes, semi-independent living, and other residential options are wrong. But they do have their limitations. In our conversations and meetings with families, the following concerns about the current residential service system for people with disabilities surface repeatedly:

- there is no control over where their relative lives
- individual needs may be secondary to those of other roommates
- someone else decides who your family member lives with
- the personality of the home is often shaped by the people who work there, not by the people who live there

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program. (Foundations began as a transitional program funded by the Ministry of Community and Social Services for young adults looking for opportunities in their community.)

Sue told Roz and Lynne about an apartment and a roommate that Beth could try on a monthly basis. They met the roommate and Beth decided to give it a try. For the next month, Beth gradually integrated into this new arrangement. During this month of gradual integration, the old Beth returned and blossomed! By the end of the month, Roz and Lynne knew Beth was very ready to move out on her own. A few days before the move, however, the place became unsafe and Beth had to return home.

Needless to say, Beth was very disappointed. Roz and Lynne promised to look for another—and safer—place to live. Every single day after that, Beth asked if an apartment had been found.

After much soul searching and budgeting, Roz and Lynne decided to purchase an apartment condo for Beth. With the help of a neighbour who was a real estate agent, the search began. As soon as Beth saw it, that was it! This was the one. It had all the things she said she needed.

So Roz and Lynne and the bank (mostly the bank) took the leap and bought an apartment for Beth. Even though Beth would have been allowed to own this apartment without losing

ODSP benefits, for Beth's protection, the apartment is in Roz and Lynne's names. It will, however, be left to Beth's trust. Through Special Services at Home and more recently, Passport Funding, workers have been hired on a very part-time basis.

If you asked Beth what she wanted for her 28th birthday, she would have answered "my own apartment." And so it was. Beth's family and supporters gathered to drink champagne that day in her new place. Foundations provided funding to hire a worker to assist with cooking, shopping, and recreation. Beth continues to work very hard at learning to live on her own.

Beth is still deciding if she wants a roommate. Because her apartment has two bedrooms, this could be a possible option in the future. And—oh yes—her bedroom is painted light pink with some hot pink accessories for contrast.

If you ask Beth what is best about her apartment she will tell you, "This is my own place and my own dreams, a place to have my friends." And so the dream touches down in reality. Beth has a home of her own. ■

The Haven Family

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- some group homes may not welcome the involvement of family and friends
 - there is no security of tenure
 - families fear the loss of caring and understanding staff and home supervisors, as these types of changes have an immediate impact on their family members
 - as a result, more and more families are looking for alternatives that provide flexibility, continuity, and greater control.

Home ownership

Homeowners have status in our society. The pride of ownership is one of our more important cultural values. Home ownership is the fulfillment of a dream even if we have a hefty mortgage and are borrowing money from a financial institution. Home ownership can also be a good investment, and a hedge against inflationary times.

Most of us take it for granted that we will own a home at some point in our lives. Until recently, this has not been the case for people with disabilities. In the past, it was a dream they and their families dared not consider. As our families members become more self-sufficient and as our plans to secure the future become more focused, home ownership for people with disabilities is becoming an option of interest. In fact, it is an option that more parents are exploring, more financial institutions are supporting, and governments are welcoming. Major home ownership initiatives are underway in Australia, the United Kingdom, and the United States. And more and more examples are being developed all over Canada.

Whether the home is owned directly by your relative, owned jointly with you or others, or owned by their trust, for as long as they like your relative will have a choice in where they live, who they live with, and in the staff they hire. As one mother put it, “Roommates will come and go, support services will change, that’s a given. But whether I am around or not, I know that the house—or I should say the home—will be there for my daughter.”

Home control means choosing:

- where you want to live
- with whom you will live
- the staff who will support you.

Critical components of home ownership

As you might expect, making arrangements for home ownership for your family member can be complicated. The mix between financial and legal matters, health and safety concerns, and social support adds more considerations. It means paying attention to a number of critical components.

Home ownership means:

- control over where you live
- stability of tenure
- the opportunity to build up equity
- privacy
- a sense of place
- choice
- ability to offer hospitality
- security
- safety and comfort.

FINANCING THE PURCHASE Unless you are independently wealthy, this is a major challenge. The Registered Disability Savings Plan (RDSP) provides families with a means to begin saving for the purchase of a home. The matching Canada Disability Savings Grant, the Disability Savings Bond, and compound interest will increase the size of the capital your relative will have available. We will explain the details of the RDSP in Step Five.

Other financing options used by families include:

- re-mortgaging the family home to access additional capital
- forming a partnership with other parents to purchase a home
- taking out a reverse mortgage
- working with local developers who, in return for zoning concessions from municipalities, will make affordable housing available
- earmarking part of their estate to establish a housing trust exclusively for the purpose of purchasing a home
- renting out the other bedrooms to help finance mortgage payments.

ASSISTANCE WITH RENOVATION The Canada Mortgage and Housing Corporation (CMHC) under two programs—the Residential Rehabilitation Assistance Program (RRAP) and the RRAP-D program—offers financial assistance to homeowners and landlords to improve their dwellings so they are more accessible to persons with disabilities. The amount you receive is based on the cost of mandatory repairs and the area in which you live. Currently, the maximum loan amounts range from \$16,000 to \$24,000. A certain amount of the loan may be forgivable, depending on income. Higher amounts of assistance

may be available in more remote areas. For further information, see Resources on page 185 in order to contact CMHC Ontario Region.

OWNERSHIP Here are some home ownership options you may want to consider for your relative:

- they have direct title
- they co-own the house with another person (for example, their spouse or a family member)
- you own the house together
- at least two families own the home
- your family member lives in a housing co-op that can build up equity
- your family member rents to own
- you arrange financing for your family member to live in a co-housing development. All financing (for each unit and the common areas) comes from the owners of all the units
- the house is owned by a trust in your family member's name (or by joint trusts if two or more people with disabilities are involved). The trust(s) can be established:
 - while you are alive; or
 - through your estate after your death.

TYPES OF CO-OWNERSHIP If more than one individual or family owns the home, then you must choose one of these legal co-ownership options:

- joint tenancy; or
- tenancy in common.

HOUSING TYPES Just about anything is possible:

- single family
- condominium or row housing
- housing cooperative unit
- co-housing
- apartment
- mobile home

Joint tenancy

Property owned jointly by two or more persons in which the surviving joint tenant(s) becomes the owner of the entire property when one of the joint tenants dies.

Tenancy in common

Property owned jointly by two or more people. Upon the death of one of the tenants-in-common, ownership of the deceased's shares is transferred to that person's estate, not to the other joint owner.

- infill housing (for example, converting a garage into a small housing unit)
- renovation of existing house
- purpose-built housing designed for your relative's needs; for example: shared kitchen, dining, and lounge areas.

ONGOING MAINTENANCE If you purchase a house, you will need to make arrangements to cover:

The ongoing mortgage payments

- Will government income assistance be enough?

If not:

- When you are alive, will you supplement the mortgage payments out of a living trust, from family resources or from some other source such as the RDSP?
- After your death, will the payments come out of a trust?

The major maintenance, repair and insurance costs as well as property taxes

- Will you pay for these costs yourself while you are alive or will you establish a living trust for this purpose?
- Will you establish a trust to cover these costs after your death?

NOTE It is critical that you consult with a knowledgeable lawyer to establish the trusts referred to above. For example, you want to ensure that you do not jeopardize your relative's entitlement

The future has
already arrived.
It's just not evenly
distributed yet.

WILLIAM GIBSON

to government benefits. ODSP has a housing cost component which is dependent on costs incurred. You may want to structure payments with this amount in mind. For more information, visit the Ministry of Community and Social Services website at www.mcscs.gov.on.ca and search for "Housing-related supports."

The minor, ongoing maintenance

While this can be done by yourself in the short term, you may want to consider contracting with a property management company to provide this service. In addition, this may be a service you will need to request your trustee to provide. If your relative lives in a condominium or a housing cooperative, property maintenance is already built into the housing agreement.

NEGOTIATING FUNDING FOR PROGRAM SUPPORT STAFF Unless you have the private means to pay for staffing supports, you will have to negotiate funding from government. Generally speaking, government is becoming more interested in supporting people to live in their own homes. After all, it represents a big savings if the capital costs of the home are not its responsibility. We suggest you use this argument when negotiating the supports necessary. You can argue that since you are financing the house, the government should finance staff supports.

SELECTING COMPATIBLE SUPPORT STAFF Not every staff person will be comfortable working in your family member's private home. Many staff will see it primarily as their workplace. We suggest you spend time clarifying in writing the values that are important to your relative. When hiring through an agency, become familiar with their operating philosophy. Interview their executive director. Visit some of their programs. Get to meet the people who receive services from them. Talk to their families.

Do not be afraid to let staff go if it appears they are not compatible with the values established for the home.

CHOOSING A COMPATIBLE ROOMMATE There is no scientific approach to this challenge. Some people are easy to get along with. Others are not. Often you won't know until you try. Many of the people who are now living in their own homes first tried living on their own in some form of rental accommodation. Then they invited someone to live with them. This is an excellent way to test the kinds of support you and your relative will need. It also enables people to have a better sense of who they want in a roommate.

TECHNICAL ADVICE FOR CONSTRUCTION AND RENOVATION

We'll leave you to your own devices with this component. You will be able to access building contractors in your area far better than we will. Accessible building design advice is available from local disability resource groups if you would like additional expertise. Other parents are a good connection for families who are considering construction or renovation. Check our resource section for additional contacts.

Looking to the future

Times are changing. More people with disabilities are about to become home owners. They are gaining a measure of choice and control over their lives that they have never experienced before. When established with due respect and consideration for the issues identified here, home ownership also provides families with a concrete component of their plan for the future.

Families see themselves as part of the solution. With tax and trust concessions, more and more families will be willing and able to invest in the housing future of their relatives with disabilities and to partner with government.

Everyone
benefits when
everyone
belongs.

This step—Creating a Home—connects with the other steps in this book. It does not exist in isolation. Without the existence of a network of personal support, our relatives will be just as isolated in their own place as anywhere else. Similarly, you will need to use your Will and trust agreement (see Step Five) to formalize the arrangements to own or rent as well as to make provisions for housing maintenance.

In addition, the next step—Making Sound Decisions—provides an overview on supported decision-making. This Step will assist you to protect your relative against exploitation in their home, to support their choices, and to monitor the home arrangements that have been made. ■

Examples of housing solutions

Given the complexity of issues and the unique circumstances of each individual and family, the following examples should serve only as illustrations of what is possible.

EXAMPLE ONE

Starting young: Jackie

Background

All Jackie wants to talk about is her last dance class, the time her choir got to go to Montreal, and the sleepover with her classmates at a local aquarium. Grade four is a time of wonder and learning.

Don and Jasvir are more serious.

Conversation reflects their concern for her security and continued happiness. “We take our choices for granted. Knowing that Jackie will have enough money to pursue her dreams is important to us,” says Jasvir. They see the RDSP as a way of ensuring that she can make personal choices when deciding her future. They want her to be able go where she wants to go, to do what she wants to do, and to make choices that make her happy.

Don and Jasvir have discussed the RDSP and are planning to contribute \$150 a month for the next 20 years. Jackie’s grandparents also want to help. They’ve talked about contributing \$25,000 to her RDSP at the start.

When Jackie is 39 years old, her RDSP will be an estimated \$362,000. If she purchases a life annuity, she will have annual income in excess of \$18,000 per year.

Another option is to use a lump sum from the plan to assist their daughter in purchasing her own home. If they withdraw \$200,000 as a down payment when Jackie is 39, she can purchase an annuity that will pay approximately \$8,000 per year for the rest of her life.

RDSP Summary:

Family taxable income: over \$78,130

Annual family contribution: \$150 a month (\$1,800 a year)

Family contributions from age 9 to 28: \$61,000 (including \$25,000 from grandparents)

Value of Grant: \$45,000

Value of Bond: \$10,000

Investments: moderate risk (estimated return 5.5%)

Age to begin receiving from the plan: 39

Approximate value of the RDSP when payments begin (age 39): \$362,000

Option A: No home purchase

Annuity payments: approximately \$18,000 per year.

Option B: Home purchase at age 39

Withdrawal of \$200,000 for down payment

Annuity payments: approximately \$8,000 per year.

EXAMPLE TWO

Patricia, living in an apartment

Background

Patricia is 38 years old and lives on her own. After sharing a rental apartment with a friend

for three years, Patricia moved into a housing cooperative where she stayed for two years.

Patricia's grandmother had left her a large sum of money which she had placed in a discretionary trust. John, Patricia's father, is trustee.

When Patricia decided to move out of the housing co-op, she and her dad decided to look for an apartment unit she could own. They found an affordable one-bedroom unit, centrally located near a large shopping centre, and close to major bus routes.

Financing

The apartment unit cost \$125,000.

Patricia's dad contributed \$12,500 of his own money.

The discretionary trust contributed \$97,500 in a no-interest second mortgage.

Patricia took out a first mortgage for \$15,000.

Features

- Patricia has title to the apartment.
- Since her dad owns only a tenth of the apartment, Patricia is the principal owner. As homeowner she is eligible for the homeowner's grant. Also since this is her principal residence, the apartment is not subject to capital gains should it ever be sold.
- The fact that Patricia's father owns approximately a tenth of the apartment prevents a dishonest person from persuading Patricia to sell or to order major repairs.
- Should the apartment ever be sold, Patricia's father would get his money back and the

amount of the second mortgage would be returned to the discretionary trust.

- The mortgage payments—plus hydro and maintenance costs—are equal to the shelter component of the ODSP benefits Patricia receives.

EXAMPLE THREE

Thomas, staying in the family home

Background

Thomas is a 48-year-old man who currently lives with his parents. They want him to remain in the family home after they die. When that day arrives, the house will be placed in a trust for Thomas's continued use. To support Thomas, the family has arranged to establish two trusts (a residential trust and a family trust) and a microboard (see page 97).

Financing

The parents' estate plan provides for the home, including furnishings, to be left in a discretionary trust for the primary use and benefit of Thomas. The family calls this the "residential trust." The trust would have a small amount of funds to cover minor repairs.

A separate discretionary financial trust will provide additional assets to cover maintenance of the home, property taxes, extraordinary expenses, and the quality of Thomas's life. The family calls this the "family trust."

Community Living Ontario will be asked to contribute funding towards the daily support

needs of Thomas. For more information, please see Resources on page 185.

Features

- Thomas continues to live in an environment that is most familiar to him.
- There will be a small microboard (see page 97). This microboard consists of three people (a family member/advocate, a co-trustee, and a Personal Network member). This microboard will have the authority to contract with CLBC. This funding will allow the microboard to contract with service providers. They will also monitor the quality of the care.
- Two or more compatible people will live in the home with Thomas and provide a caring and harmonious living environment. In return, they will live rent free and enjoy the home as is customary under traditional rental contracts.
- Should it become necessary to sell the home, the Will contains a provision that the trustees can do so and use the funds from this transaction to acquire an equivalent home for Thomas's benefit. Any surplus funds will be placed in the family trust.
- As the trust owns the property, it will most likely not qualify for the homeowner's grant or supplement.

EXAMPLE FOUR

Surinder, living in a condominium near the family home

Background

Gopal and Dal purchased a two-bedroom condominium for their 28-year-old son, Surinder. The complex is located within three blocks of the family home.

Financing

Total cost of condominium: \$170,000.

Down payment from the parents: \$140,000.

Surinder's monthly mortgage payments are approximately \$300 over a twenty-year period.

Features

- Ownership of the home is between the parents and Surinder. As financial protection, Surinder granted his parents a Continuing Power of Attorney for Property.
- Upon the parents' death, complete ownership of the home goes to Surinder. Surinder's sister and her husband will have Continuing Power of Attorney over Surinder's property.
- One of the bedrooms will be rented to a roommate for Surinder.
- A team comprised of a representative of the family, the service delivery organization, and the family of Surinder's roommate will oversee the maintenance and operation of the condominium.

The making of a sanctuary

FOR ONE GLORIOUS SUMMER in the 70's, an old tamarisk tree with wide branches sweeping down to the sand of a Greek beach was my home. Its branches opened like welcoming arms to form my front door. When friends came to call they knew I was home if they saw my sandals carefully set to one side. Inside there was a special crook in one branch that held my cup and toothbrush and plenty of twigs to drape my scarves on. My tree gentled the sun's rays by day and let the stars peek through at night. I felt safe and sheltered by this kind tree. My tree space felt lived in, by me, by others before me and of course by various wildlife who shared it with me. It was definitely the place that felt the most like home during that sun-kissed summer.

One of our treasured family stories is the account of my mother, who upon reading a letter containing my starry eyed account of my life in Greece, burst into tears and wailed, "She's living in a tree. A tree!" For her, my breezy home was not and never would be a home.

That's the thing about a home. It is a very personal feeling. Not so much a place as a space. It is a space that breathes and nourishes us. A space becomes a home when it opens to us as we are, and when we, in turn, get worn into it.

Creating this kind of home space when a person is vulnerable or isolated is complex. As families we are often caught in the paradoxical challenge of finding spaces that both open doors and secure locks. This is why cultivating and consulting caring connections beyond us is so

important for our relatives. Standing together, we can peek out, open the curtains of our own comfort zones and imagine the living, breathing spaces our relatives can grow their way into. And out of.

Just as no tree lives for forever, no home, no matter how well planned, financed and built, is ever permanent. True durability lies in the long arms of others who will care for our relatives beyond our lifetime. It is an embrace that will nourish and honour the spirit of our relatives wherever they may live. ■

Vickie Cammack

Worksheet 6

Welcome mat

These are questions you can discuss with your relative. Have some fun and use a variety of props to facilitate your discussion: perhaps have your relative draw a few pictures or make a collage of cutouts from magazines.

What kind of home would you like to live in? _____

Would you like to live by yourself or with other people? _____

Who would you like to help you live in your own home? _____

What would this person help you with? _____

Where do you want to live? _____

Why do you want to live there? _____

What do you want to live close to? (a park, church, recreation centre, bus route, shops, and so on.) _____

What is your favourite room? _____

Do you have a favourite chair? Would you like to have one? Which room would you place it in?

Where would you place your favourite things? _____

What kind of furniture will you need for your own place? _____

What furniture from your family home would you like to have in your own home? _____

Would you keep a pet? What kind? _____

Would you like a garden? _____

Do you like to cook? If so, would you like to have a big kitchen? _____

Would you like to have a quiet room? _____

Which room would you like to have music in? _____

Do you like doing dishes? _____

Do you like to clean the house? _____

Do you like to mow the lawn? _____

How would you decorate:

Your living room? _____

Your bedroom? _____

Your entrance? _____

What colour would you paint the outside of your house? _____

How would you welcome visitors to your home? _____

When you came home at the end of the day, what would be the first thing you would do?

Worksheet 7

When is a house a home?

Here are some simple guidelines and questions to help you evaluate the home-like quality of residential services.

Whose house is it?

Are the individuals who live in the house the ones to determine its structure and tone or is the house geared to suit the staff hired to provide service?

Use your home and your own life as yardsticks for comparison. Do not accept, “well, it’s better than where they were.” Instead, ask yourself, “Is it as good as I have now?” and “Is it as good as I would want for myself?”

Look around

Are there locks where they are not needed; that is, on the refrigerator, on the clothes closets, and so on?

Are there no locks where they are needed; that is, on bathroom doors, bedroom doors, filing cabinets, medicine cabinets, and so on?

Do people have the same amount and variety of possessions and personal articles as other people their age?

What does it feel like?

Are the rooms comfortable? How about the couch? The chairs? Could you relax here? Does the place feel like a home?

Take a moment to listen

Can you go somewhere for a little peace and quiet? Are there conversations among the people who live here?

Smell

Do you get a scent of home made dinner on the stove or dessert in the oven, or do you smell institutional cleaners and odors?

Taste

Would you enjoy the food that is served or would you merely tolerate it?

Ask

What are the rules? Are they excessive or overly restrictive? Do they make sense to you? Who makes the rules?

Infer

Do the people who live here experience a home with some added support, programming, and needed supervision? Or do they experience an institutional program with a few home-like qualities?

Analyze

What compromises have been made in the name of budget limitations, programming practices, staff needs, and so on? In what ways do these compromises detract from a home-like atmosphere?

Ask yourself

If an opening came up tomorrow, would I ask to move in?

