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A resource for planning housing and support



#### PREPARED BY

Summer Foundation Ltd PO Box 208, Blackburn 3130 Victoria Australia TELEPHONE +61 3 9894 7006 FAX +61 3 8456 6325 EMAIL info@summerfoundation.org.au www.summerfoundation.org.au

#### PREPARED FOR

Australian Government Department of Families, Housing, Community Services and Indigenous Affairs The opinions, comments and/or analysis expressed in this document are those of the author or authors and do not necessarily represent the views of the Minister for Disability Reform and cannot be taken in any

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The moral right of the author has been asserted.

PRODUCER Kate Carmichael DESIGNER Andrew Budge, Designland PHOTOGRAPHER Fred Kroh NARRATOR Kat Stewart VIDEO EDITOR Jodie Gallacher FOOTAGE ACQUISITION Inspireworks

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#### **Glossary of terms**

#### Attendant Carer (See Disability Support Worker)

**Case Manager** A Case manager works with a person and their support network to plan and coordinate the appropriate treatment, services and support.

**Cluster of Units** A group of separate units that can be purchased or rented by people with disability who wish to share onsite support from disability support workers.

#### **Continence Aids Payment Scheme (CAPS)**

The CAPS is an Australian Government Scheme that provides a payment to assist eligible people who have permanent and severe incontinence to meet some of the costs of their incontinence products. The payment is made by Medicare directly into a client's nominated bank account.

http://www.bladderbowel.gov.au/caps/

DisabilityCare Australia, a national disability insurance scheme DisabilityCare Australia, a national disability insurance scheme, will provide long term support for people who have a permanent disability that significantly affects their communication, mobility, self-care or self-management. It will focus on intensive early intervention, particularly for people where there is good evidence that it will substantially improve functioning or delay or lessen a decline in functioning. It will also include a comprehensive information and referral service, to help people with a disability who need access to mainstream, disability and community supports.

**Disability Support Worker** Disability support workers provide assistance to a person with everyday tasks that a person without a disability would be doing for themselves and may include the following personal activities: lifting, showering, toileting, grooming, meal assistance, meal preparation, exercise, domestic responsibilities, recreation, personal development, communication, mobility, personal administration, shopping and other independent living skills. (Also called Attendant Carers). **Moveable Unit or Bungalow** Movable units are fully self-contained units that can be set up in the backyard of a friend or relative's home. They are designed to help older people or people with support needs, keep living independently while maintaining close contact with family and friends.

The units are suitable to accommodate one or two people and include a one or two bedroom unit with an en-suite bathroom/toilet/laundry, and a living room with an annexe kitchen.

http://www.dhs.vic.gov.au/for-individuals/ housing-and-accommodation/home-owner-support/ movable-units

**Neuropsychologist** A Neuropsychologist understands how brain damage can affect thinking, memory, behaviour and personality. They perform assessments to identify which functions have changed and suggest strategies to help manage those changes.

**Occupational Therapist (OT)** An Occupational Therapist assesses the ability to manage daily tasks and recommends home modifications or physical aids that may be needed to perform tasks. They also help people re-learn skills, such as how to dress, prepare meals and maintain hygiene.

**Physiotherapist** A Physiotherapist works on a person's ability to move, coordinate and balance, and helps to relieve muscle stiffness and develop exercise programs. They also assess the need for mobility aids, such as wheelchairs.

**Shared Supported Accommodation** A house where usually 4–6 people with disability live with onsite support from Disability Support Workers (also called a Community Residential Unit (CRU) or group home).

**Social Worker** A Social Worker helps people locate special accommodation needs, useful community and government services, support groups and provides advice on welfare benefits.

**Speech Pathologist** A Speech Pathologist helps overcome problems with communication, speaking and swallowing.

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#### Introduction

#### What is the Housing Toolkit?

The Housing Toolkit is a resource designed to assist you in making decisions about the type of housing and support that would suit your lifestyle, preferences and needs.

#### How was Housing Toolkit developed?

The Summer Foundation has worked closely with people with disability and their families to understand the experiences, issues and concerns about housing and support. Throughout this consultation process, the aim was to create a toolkit that is relevant and user-friendly, to help people make their own choices.

#### How do you use the Housing Toolkit?

The Housing Toolkit provides a comprehensive planning tool to assist you to plan for your future. The toolkit provides step-by-step information, questionnaires and checklists that have been designed to help you consider various options for housing and support.

The DVD and booklet provided in the toolkit includes other people's stories of housing and support, showing different options that relate to where a person lives and the type of support they receive. These stories are designed to help you think more about the type of housing and support that would suit your lifestyle.

The toolkit has been divided into sections. You may find that it works best for you to complete one section and skip others in the first instance. Alternatively, it may suit you to work through the whole book. The toolkit is designed to be flexible to meet your individual needs. The aim of the toolkit is to help you think about your journey in steps. You may have an ideal vision for your life and can use the toolkit to plan out all the steps to achieve this. Alternatively, you may feel unsure about the possibilities and use the stories, checklist and other resources to make an initial plan. Each section is designed so you can go back and include new ideas, change your plans and add more detail. You can photocopy pages, or add other documents to this housing toolkit if required.

You may like to work through the toolkit on your own, or discuss the possibilities with family or friends, or with a support person such as a worker or case manager. Before you get started, you could think about the things that you would like to change about your current situation, and also the things that work well for you now, and which you would like to see continue into the future.

#### What do I do with the information I put into the housing toolkit?

You can decide who you share this information with. You may like to share this information and discuss it with friends, families or workers. You may also want to enlist others to help you consider your goals, dreams and needs for community living.

If you would like some additional support or information on how to use the toolkit, you can contact the Summer Foundation on 1300 626 560.

We wish you all the best for your future.

**Dr Di Winkler**, CEO Summer Foundation Ltd May 2013

#### What is the Summer Foundation?

The Summer Foundation is a non-profit organisation that aims to resolve the issue of young people in nursing homes. The Summer Foundation's vision is that young people with disability and complex care needs will have inherent value as members of society, with access to services and housing that supports their health and well-being.

#### Acknowledgements

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Real life examples

## About me



#### **Personal information**

Name:			
Address:			
Phone number:			
Email address:			
DOB:		Current Age:	
Gender:	O Male	) Female	
Are you an Aboriginal or	r Torres Strait Islander?		
Main language spoken:			
Key contact/support per	rson:		
Relationship:			
Phone number:			
Email address:			

#### My journey

This is a space for you to write about your journey and your life. You may like to write about your childhood, school or work, and the things you like to do, your achievements or significant events. You may like to talk about your cultural heritage, customs or your faith/community if any of these are important in your life. You may find you would like some assistance from another person who knows you well to write this. Write down as many things as you would like to about your life now.



#### In five years time I see myself:

The significant occasions I like to celebrate are:

The three most important things I want people to know about my life so far are:

1.

2.

3.

Write down your favourite things here. There are extra lines for any other things you would like to add.

My favourite food

My favourite activities

My favourite places to go

My favourite TV show(s)

My favourite movie(s)

My favourite people to spend time with

My top three favourite things are:

1. 2. 3.

#### Choices and decision-making

Making our own choices and having control over decision-making are important aspects of life for all of us. This table will help you think about the areas in which you feel supported to make your own choices.

Areas of choice and decision-making	I currently have the opportunity to make choices about this	l would like to have more choice in this area	l am not too concerned about this
What I have for my meals	0	0	0
The time that I have my meals	0	0	0
The leisure activities and hobbies I take part in	0	0	0
Planning my week	0	0	0
Planning my day	0	0	0
Household routines (e.g: shopping, cleaning)	0	0	0
When and where I go out (e.g: cinema, footy game, pub)	0	0	0
The time I get up in the morning	0	0	0
The time that I go to bed	0	0	0
The clothes I wear each day	0	0	0
How I spend my money	0	0	0
Whom I live with	0	0	0
Where I live	0	0	0
Keeping pets	0	0	0
Recruitment of support staff	0	0	0
Removing unsuitable support staff	0	0	0
Time and privacy for intimate relationships	0	0	0
Where I keep my possessions	0	0	0
The furnishings in my home and bedroom	0	0	0
Going on holidays	0	0	0
Opportunities for employment or study	0	0	0
Access to private spaces	0	0	0
Other (list):	0	0	0

1. Hatton. C., Emerson, E., Robertson, J., Gregory, N., Kessissoglou, S. and Walsh, P.N. (2004).

# My interests and community connections



#### The roles I play in my family and community

Thinking about the different roles in your life, tick each box below that is relevant to you. There may be roles listed that you are not currently undertaking but would like to sometime in the future. There is some space for you to write notes.

Life Role	
Partner	
OI am currently doing this	O I'd like to do this
Student	
OI am currently doing this	O I'd like to do this
Worker	
OI am currently doing this	O I'd like to do this
Volunteer	
I am currently doing this	○ I'd like to do this
Caregiver (e.g. to children, eld	lerly parents)
I am currently doing this	◯ I'd like to do this
Home maintainer (e.g. garden	iing, cleaning)
I am currently doing this	◯ I'd like to do this
Friend	
I am currently doing this	◯ I'd like to do this
Family member	
I am currently doing this	○ I'd like to do this
Religious participant	
I am currently doing this	) I'd like to do this
Hobbyist (e.g. swimming, fish	ing, visiting museums)
I am currently doing this	) I'd like to do this
Participant in organisation or	club (e.g. Rotary)
I am currently doing this	○ I'd like to do this
Other	
I am currently doing this	◯ I'd like to do this

2. Adapted from Barris, R., Oakley, F., and Kielhofner., G. (1988).

#### My hobbies and community involvement

During the week I am involved in the following activities/hobbies:

On the weekends I am involved in the following activities/hobbies:

Am I involved in any paid employment? (e.g. working for an employer or self employed)

Would I like to find paid employment?

Do I volunteer in my community?

What type of volunteering would I like to do?

Am I doing any study? (e.g. School, TAFE, University)

If I would like to study, what would I like to study?

# My current home



#### Where I live now

Where do you live now? Write down what works for you, and what doesn't. Think about any aspects that you would like to remain the same.

Where I currently live:

The features of my current home are: (eg. safety, accessibility, comfort):

Thinking about the local area in which I live, what stands out to me the most is: (e.g. the environment, neighbours, services, shops etc)

The most important things I would say about my current home are:

.....

1. ..... 2.

3.

The best thing(s) about where I live now is:

I am close to:

The aspects of where I live that I would like to remain the same are:

The worst thing(s) about where I live now:

I want to be closer to:

I want to be able to:

### My current week

# A CONTROL SUN

#### My typical day

What does my typical day look like?
Morning:
Afternoon:
Evening:
Overnight:
Are my days on the weekend different to a weekday? O Yes O No
If yes, please describe how the weekends are different:
The most important or enjoyable parts of my day are:
The most important or enjoyable parts of my week are:

#### My weekly timetable

You can use this timetable to show how you spend time each day of the week.

	Monday	Tuesday	Wednesday
Mornings			
6.00 - 6.30			
6.30 - 7.00			
7.00 - 7.30			
7.30 - 8.00			
8.00 - 8.30			
8.30 - 9.30			
9.00 - 9.30			
9.30 - 10.30			
10.00 - 10.30			
10.30 - 11.00			
11.00 - 11.30			
11.30 - 12.00 PM			
Afternoons			
12.00 -12.30			
12.30 - 1.00			
1.00 - 1.30			
1.30 - 2.00			
2.00 - 2.30			
2.30 - 3.00			
3.00 - 3.30			
3.30 - 4.00			
4.00 - 4.30			
4.30 - 5.00			
Evenings			
5.00 - 5.30			
5.30 - 6.00			
6.00 - 6.30			
6.30 - 7.00			
7.00 - 7.30			
7.30 - 8.00			
8.00 - 8.30			
8.30 - 9.00			
9.00 - 9.30			
9.30 - 10.00			
10.00 - 10.30			
10.30 - 11.00			
11.00 - 11.30			
11.30 - 12.00 AM			
Overnight			
•••••••••••••••••••••••••••••••••••••••			

Thursday	Friday	Saturday	Sunday
••••••			

List any additional information about your overnight support requirements on the previous page's timetable below:


# My current supports



#### My circle of support Informal supports

This page will help you decide who the important people are in your life. This may include family, friends, neighbours and others. You can write as many or as few names as you like.

You will find links to helpful information on building formal circles of support in the Information and Resouces section on page 73.

#### Structured supports Current support

Now we will look at the type of support you currently have each day. Using the table below include information about any of the support services you currently use that are listed.

Type of support	Tell us more about the support services you would like to access
Allied health services (e.g. physiotherapy, neuropsychology, occupational the	rapy)
OI currently access these services OI would like to access these services in	n the future
Medical team (e.g. GP, Neurologist)	
OI currently access these services OI would like to access these services in	n the future
Home Services (e.g. laundry, gardening, house cleaning)	
OI currently access these services OI would like to access these services in	n the future
Community services (e.g. meals on wheels, sharps/pad disposal)	
OI currently access these services OI would like to access these services in	n the future
Medications I take	
OI currently take medication OI may need to take medication in the future	·
Consumables (see Appendix C checklist)	
OI currently use consumables OI may need to use consumables in the future	ure
Access to private spaces	
OI currently access private sapces I would like to access private spaces i	n the future
Other	
I currently access these services I would like to access these services ir	n the future

The most important support services I currently access are:

Are there any areas in which I would like to increase or decrease the amount of support I receive?

#### My current support needs

This table can help you work out your current level of support each day from various sources. Writing down information about your current supports will help you think about your needs for the future.

#### My current support needs

Type of support	Hours (per day/week/ month, please specify)	How many people assist me?	Am I happy with the amount of support?
Support from family or friends			
Daytime			
Overnight			
Disability Support Worker/Personal Care Assistant			
Daytime			
Overnight			
Case Management			
Nursing			
Daytime			
Overnight			
Other People			
Daytime			
Overnight			

6. Adapted from Winkler, D., Sloan, S., and Callaway, L. (2007)

#### My independence

Have a think about the things you would like assistance with each day and things that you may only need assistance with occasionally.

Things I need help with everyday	Things I need support with occasionally
The things I would like to do more independently are:	
The things I would like to have more support with are:	

#### **Skill development**

Over the next two pages we have listed skills that you may like to develop over time. Tick all of the skills that you would like to develop. Feel free to write down any thoughts on how you would like to do this or what resources or supports you would need to develop the skills in the notes section.

Activity	I currently need assistance with these skills Tick all that apply	I would like to develop these skills Tick all that apply	Notes or comments Write down any information about how you would go about developing skills and any supports or resources you may need
Personal care			
Eating and drinking	0	0	
Bathing or showering	0	0	
Dressing/undressing	0	0	
Grooming (teeth, hair, face)	0	0	
Toileting (daytime)	0	0	
Medication management	0	0	
Specific nursing care	0	0	
Intimacy and relationships	<u> </u>	0	
Overnight support			
Sleeping	0	0	
Bed mobility	$\bigcirc$	0	
Toileting (night time)	<u> </u>	0	
Transfers and Mobility			
Bed transfers (in and out)	0	0	
Chair transfers (in and out)	0	0	
Shower transfers (in and out)	0	0	
Toilet transfers (in and out)	0	0	
Car transfers (in and out)	0	0	
Indoor mobility	0	0	
Community mobility	0	0	
Stairs (up and down)	0	0	

Activity	l currently need assistance with these skills Tick all that apply	l would like to develop these skills Tick all that apply	Notes or comments Write down any information about how you would go about developing skills and any supports or resources you may need
Household tasks			
Meal preparation	0	0	
Laundry	0	0	
Light housework	0	0	
Heavy housework	0	0	
House and garden maintenance	0	0	
Community activities of daily living			
Banking	0	0	
Personal shopping(e.g. toiletries)	0	0	
Grocery shopping	0	0	
Public transport use	0	0	
Communication			
Talking with familiar people	0	0	
Talking with unfamiliar people	0	0	
Reading	0	0	
Writing	0	0	
Telephoning	$\bigcirc$	0	
Computer use	$\bigcirc$	0	
Other:	0	0	
	$\bigcirc$	0	
	0	0	
	0	0	

6. Adapted from Winkler, D., Sloan, S., and Callaway, L. (2007).

#### My equipment

The equipment you use can greatly assist you in being more independent. Have a think about the equipment you currently use and list it below (e.g. electric wheelchair, hoists, shower chair, iPad, laptop).

Intrathecal pumps Shower trolley	0 0 0
Shower trolley	0
	0
Shower chair	
Continence Equipment	$\bigcirc$
Hoist (ceiling or portable)	0
Wheelchair (manual or motorised)	0
Mobility aid (e.g. walker)	0
Specialised seating	0
Personal care equipment (e.g. cutlery, lidded cups)	0
Bed	0
Pressure care mattress & overlays	0
Handrails	0
Environmental control unit	0
Other (list):	0
	0

6. Adapted from Winkler, D., Sloan, S., and Callaway, L. (2007).

# My finances



#### Important areas of financial management

You may like to start thinking about your finances and any financial matters that you would like to take care of. Here are some things you may like to consider:

What level of funding/support am I currently entitled to?

What debts do I have and how will I manage them?

Superannuation (Am I currently working and receiving superannuation contributions from my employer or have I received contributions from

previous past employment?)

How will I manage any funding and support that I receive? Who will help me to manage my finances if required?

What kind of insurance should I have?

Should I speak to a Financial Advisor/Counsellor?

I have children; how can I support them into the future?

Should I draft a Will?

3. Adapted from Etmanski, A. (2000).

#### Money management checklist

You can use this checklist to think about your financial situation, the things you want to manage yourself or the areas in which you would like some assistance.

Am I confident/capable of managing my money for daily living? (e.g. shopping, paying bills)		
◯ Yes ◯ No │ Notes		
What type of assistance would I like for managing my money? (e.g. education, technology to access banks, support from family/		
friends/workers)		
What are my current income sources? (amounts of benefits, wages, other income, and when received)		
What are my regular expenses? (rent or mortgage, bills, housekeeping, other spending)		
Have I made legal arrangements for managing my financial affairs? (e.g. appointees for benefits if required)		
O Yes O No Notes		
Do I have an existing bank account, or does one need to be organised?		
◯ Yes ◯ No │ Notes		
Have I developed an action plan to assist me in managing my money?		
○ Yes ○ No │ Notes		
Have I prepared a budget?		
○ Yes ○ No Notes		
In a shared house, which costs are charged to the individual and which are shared amongst co-residents?		
◯ Yes ◯ No │ Notes		

4. Adapted from Pannel, J. and Harker, M. (2007)

#### My current funding sources

List here the sources of funding that you receive.

Source of funding/income	Amount in dollars \$	How frequently is the income received (e.g. weekly, monthly)
### My current budget

You can use this table to plan out your current budget and expenses. Some of the items on the list may not apply to you, and you may like to add other items in the space provided.

My budget is calculated (please tick one) O Weekly O Fortnightly O Monthly	
Item	Cost
Housing costs (rent, mortgage)	
Personal care supports	
Travel (e.g. buses, taxis, train, air travel)	
Utility bills	
Food	
Clothing	
Essential personal items (e.g. toiletries)	
Essential household items (e.g. furnishings, toilet paper)	
Other personal expenses	
Telecommunications (e.g. phone bills, internet)	
Activities/hobbies	
Holidays	
Insurance (e.g. Life insurance, home and contents insurance, private health insurance)	
Savings	

l would like to mana	age my own budget/finances:
◯ Yes ◯ No	Notes
l would prefer some	e assistance from another person to manage my budget/finances:
🔾 Yes 🔿 No	Notes
I would need the fo	llowing support to manage my own budget:
The following is a li	st of skills that I think I could develop over time to become more independent in managing my own budget/finances:
••••••	

# My hopes and dreams for the future



### Hopes and dreams

We all have hopes and dreams for our lives. Spend some time thinking about your life, the things you look forward to or would like to do in the future—your vision for the future—and write them down here.

My dreams for the future are: I would like to work or study in the following areas: Where would I like to go? The things I would like to learn are: The activities or interests I would like to continue or try out are:

# My goals for community living



When thinking about living in a community, the following things are important to me:

Some key goals I would like to achieve in community living include (e.g., joining a sporting club, attending a local community resident meeting,

My Goals	How will I achieve this goal?	What support will I need to support this goal?	What are the financial costs I need to consider?

or getting to know my local shops or cafes):

# My potential housing and support options



#### Thinking about potential housing and support options

Please review the toolkit DVD and/or read the real life examples in this folder. These resources provide some examples of housing and support options people have chosen. They are designed to help you think about how an ideal housing and support model would work to suit your lifestyle.

This diagram will help you think about the important elements of a housing and support solution that may suit you. You can write some notes about the information in the diagram to help you think about the most important things.

#### **Basic needs**

Health Equipment & consumables Eating, swallowing & communication Behaviour

#### Quality of life

Role participation Community Inclusion Social and family relationships

#### Living options

Range of locations & models of support Innovative solutions Real choice

Notes

#### Things I like and dislike about models of housing and support

Now that you have either watched or read the real life examples in the toolkit, have a think about what you would like your ideal home to look like.

The model/s of housing and support that I liked were:

The reasons I liked these were:

The model/s of housing and support that I didn't like were:

The reasons I didn't like these were:

My ideal living situation (including the location, kind of housing, support I receive and who (if anyone) I may like to live with) is:

# My future home



### What I would like my ideal home to look like

The information on the next two pages looks at the features of your ideal home. Tick the boxes that are most relevant to you.

Location
O Family home/private residence at the following address:
O Suburb(s)/town(s). Please list:
O Local Government Area . Please list:
Please select from the list below. You may tick as many boxes as you like.
O Proximity to the shops
O Proximity to other community facilities
O Safety of the local community, no busy road
O Accessibility of the local environment
O Proximity to public transport. Please specify which of these is most important to you:
○ Tram
Bus
O Train
Other: Please include any other factors about the location:

#### I would like to live with (tick as many boxes as you like):

ONo-one, will not consider living with anyone	○ Family members
⊖ Friends	O People without disabilities
O People with disability	O People my own age
Males	○ Females
O People I can communicate with	O People I can share interests with
Other	O I don't mind

#### The number of people I would like to live with:

O I'd like to live by myself	One other person
🔿 2-4 other people	○ 5–10 other people
O More than 10	$\bigcirc$ I'd like to live with my family
○ Other	

#### The type of housing I would like to live in:

O My own home/private family home	◯ A house
○ An apartment	
A self-contained flat sharing support with other people with disa	
-	O A share house, living with other people with disability.
A share house, living with people without disability	O A hostel
Other, please list:	

#### The particular features of my ideal home include (tick all relevant features and include information you feel is important):

O Accessible entrances	O Bedroom
O Bathroom/toilet	O Lounge room
⊖ Kitchen	O Laundry
🔘 Garden	O Internal doorways/layout
○ Flooring	◯ Storage
O Alarm/intercom	O Secure entrances
O Private spaces	Other (Please list any other items you may think of below)

The most important features of my ideal home are:

There are some checklists in Appendix E (page 68-69) that cover a variety of questions you may like to think about in assessing whether a housing option is the right one for you.

# My future supports



#### Future support for my ideal life

Now it's time to think about the type or amount of support you would like in the future, and whether this may vary from your present situation. You may not be quite sure, and that's okay. You can refer back to the table on Page 25 where you listed the amount of support you receive each day to start thinking about future support needs.

You may need additional support in the future to take part in activities in the community or things you would like to do more of. You may also feel that you would like more support in some areas and greater independence in others. This may change over time so think of your plan as a work in progress.

Changes to my support needs For each of the items indicate if you think your support needs will change or not

Support from family and friends			
Daytime	🔿 Don't Know	◯ Yes	◯ No
If yes, how would this be different?			
Overnight	🔿 Don't Know	◯ Yes	◯ No
If yes, how would this be different?			
Disability Support Worker/ Personal Care Assistant			
Daytime	🔿 Don't Know	) Yes	🔿 No
If yes, how would this be different?			
Overnight	🔿 Don't Know	) Yes	🔿 No
If yes, how would this be different?			
Case Management	🔿 Don't Know	) Yes	🔿 No
If yes, how would this be different?			
Nursing			
Daytime	🔿 Don't Know	) Yes	🔿 No
If yes, how would this be different?			
Overnight	🔿 Don't Know	◯ Yes	⊖ No
If yes, how would this be different?			
Other people			
Daytime	🔿 Don't Know	) Yes	⊖ No
If yes, how would this be different?			
Overnight	🔿 Don't Know	◯ Yes	◯ No
If yes, how would this be different?			

5. Adapted from Queensland Helath (2010)

#### Structured supports and how they may change

Can you identify any challenges or concerns for the future if making changes to your current supports? This may include health concerns, communication challenges or uncertainty about change. Write them down in the table below:

My concern or challenge	
This worries me because	
To overcome this concern I will need the following support	
My concern or challenge	
This worries me because	
To overcome this concern I will need the following support	
My concern or challenge	
This worries me because	
To overcome this concern I will need the following support	
My concern or challenge	
This worries me because	
To overcome this concern I will need the following support	
My concern or challenge	
This worries me because	
To overcome this concern I will need the following support	
My concern or challenge	
This worries me because	

To overcome this concern I will need the following support

#### My activities and hobbies

On page 13 you listed your current activities, hobbies and commitments. Now that you are considering future plans, you may like to think about other options.

Are there activities, hobbies or formal commitments that I would like to continue with?

Are there activities, hobbies or formal commitments that I no longer wish to continue?

Are there other activities, hobbies or formal commitments that I would like to start doing that I am not doing at the moment?

Are there any one-off experiences that I would like to try? (e.g. travelling)

### My equipment

Is there any equipment you would like to start using? A detailed list of equipment and consumable products is included in Appendix C and D (pg. 66-67) that may assist you to complete the table below.

I would like equipment to assist me with	Tick all that apply	The type of equipment that would assist me includes:
Getting around	0	
Talking to people	0	
Being comfortable (physically)	0	
Being comfortable (emotionally)	0	
Accessing the internet/computer	0	
Taking part in my activities and interests	0	
Household chores	0	
Daily living	0	
Other	0	
	$\bigcirc$	
	0	
	0	
	0	
	0	
	0	
	$\bigcirc$	
	0	
	$\bigcirc$	

The most important pieces of equipment for me are:

#### My ideal disability support agency and support worker

What would the ideal disability support agency and support worker look like to you? Here are some ideas to help with your planning.

The current nercon	would have a m	reconstful reliable	tructurerthy kind of	rood conco of humaur	nationt profossional)
The subbort berson	would be, te.g.	respectiul, reliable	. ITUSI WOTITIV. KITIQ. §	2000 Sense of humour.	patient, professional)
· · · • • • • • • • • • • • • • • • • •			,	,	F

Gender, age

The important things for me to look for in a support organisation are:

I would assess which organisation best suits my needs by:

I would expect support workers to have these qualifications/experience:

Write a brief job description/guidelines for key workers:

The Mamre Association has developed some helpful information and questions to think about when planning supports, as well as when recruiting support workers. You can find a link to the Mamre website in the Information and Resources section on page 73.

# My future healthcare planning



#### Thinking about future healthcare planning

Future healthcare planning is the process of discussing and documenting your future health care choices in the event you are unable to make decisions yourself, due to illness or the progression of your disability.

#### Future healthcare planning can include:

• Deciding what future health care you would want to receive

• Discussing future treatment options with your doctor

• Ensuring your choices to refuse particular treatments are communicated and documented

• Discussing your decisions with your family, friends and those you trust

#### Some key points to think about are:

Future support/medical care needs

• How my disability affects me today

Choosing someone to speak for me

Informing others

Have you spoken to your family or friends about future health care planning?

◯ Yes ◯ No │ Notes

5. Adapted from Queensland Health, (2010)

# My transition plan



#### Transition

Thinking about where you would like to live and the supports you would like in the future, take some time to think about your transition to your new living circumstances.

Refer back to the table on Page 12 where you listed your different roles. What roles/daily living skills do you need to consider as part of your transition? These may be things you want to work on or that you feel could be challenging in the future.

Appendix B (pg. 65) can be useful when thinking about transition planning.

#### Your plan for transition

Think about your plan as a step-by-step process. You may like to list the key milestones for each step of the plan.

Steps for my transition	
1	
2	
3	
4	
5	
6	
7	
8	
9	
10	
11	
12	
13	
14	
15	
16	
17	
18	
19	
20	

Now that you are thinking about housing and support solutions to suit your lifestyle, have a think about your goals and how you may achieve these. It doesn't matter if you don't have all the answers right now, you may like to just think about the first steps you will take.

oals 1 like to live long term? supports would I like? like to spend my time?	<b>How I will get there</b> What steps will I need to take t reach my goals?
I like to live long term? supports would I like? like to spend my time?	What steps will I need to take t reach my goals?
I like to live long term? supports would I like? like to spend my time?	What steps will I need to take t reach my goals?
supports would I like? like to spend my time?	reach my goals?

I have some concerns about my plan, listed below:

Summary of my planning



Throughout the housing toolkit you will have made notes on each page highlighting the most important aspects of your life, what you are looking for in a model of housing and support, and the things you will need to achieve your goals. Use these pages to summarise your living situation and your hopes for the future.

The thing(s) I would most like people to know about me:

The most important things in my life are:

My favourite things are:

Key people in my circle of support are:

The services I currently access are:

I would like to be more independent with:

The areas I would like more support with are:

My dreams for the future are:

The challenges I will face are:

The things I want to do more of are:

The key aspects or features of my ideal home are:

The key steps in my transition are:

The things I will need to do to reach my goal are:

I will need to work through the following financial considerations:

The way I am going to plan for my future healthcare needs:

# Thoughts, notes and comments



## My thoughts, notes and comments

Here is a space for you to write down any thoughts you like.


#### Family and supporters' comments

This section is for your family and supporters to make notes, comments and add any information that may be useful to you in the future. They may like to include important dates for the family, any medical information that may be relevant or their own thoughts on your plan. You could also ask family and supporters to think about the type of support they currently provide and what will work for them in the future.

I think the ideal living situation for my family member/friend is:

I would like my family member/friend to access:

I would like the future for my family member to look like:

# Appendices



## Appendix A Support services

Below is a list of different support services that you may call upon.

	Tell us more about the support services you would like to access
Allied health services (e.g. physiotherapy, neuropsychology, occupational therapy)	
○ I currently access these services ○ I would like to access these services in the future	
Home Services (e.g. laundry, gardening, house cleaning)	
O I currently access these services O I would like to access these services in the future	
Community services (e.g. meals on wheels, sharps/pad disposal)	
O I currently access these services I would like to access these services in the future	
Medication	
O I currently take medication I may need to take medictation in the future	
Consumables (see Appendix C checklist)	
○ I currently use consumables ○ I may need to use consumables in the future	
Equipment (see Appendix D)	
O I currently use equipment O I may need to use equipment in the future	

6. Adapted from Winkler, D., Sloan, S., and Callaway, L. (2007).

## Appendix B Transition considerations

For each item below, chose how significant it is in your life at the moment. You can also put comments in the last box to help you think about this and how you may manage each item in the future. There is space below to add more items.

Medical/health support needs	O Very important	O Somewhat important	O Not important	🔿 Not known
Comments or action points				
Mental health supports	O Very important	O Somewhat important	O Not important	🔿 Not known
Comments or action points				
Communication	O Very important	O Somewhat important	O Not important	🔿 Not known
Comments or action points				
Challenging behaviour	O Very important	O Somewhat important	O Not important	🔿 Not known
Comments or action points				
My roles and interests	O Very important	O Somewhat important	O Not important	🔿 Not known
Comments or action points				
Involvement in the community	O Very important	O Somewhat important	O Not important	🔿 Not known
Comments or action points				
Community integration	O Very important	O Somewhat important	O Not important	🔿 Not known
Comments or action points				
Other:	○ Very important	O Somewhat important	O Not important	🔿 Not known
Comments or action points				

The things that have/will have a significant impact on my life are:

6. Adapted from Winkler, D., Sloan, S., and Callaway, L. (2007).

## Appendix C Consumable products you may use

This is a list of products that you may use in daily life. Tick which of the products you currently use and write how often you would need to use each one. This will help with planning your finances and budgeting. If you can think of other things please include them on the list too.

Consumable	How often I use these items (per day, per week or per month):
Continence aids	
◯ Kylies	
Condom drainage	
◯ Urine bottles	
O Pads / pull-ups	
O Indwelling catheter	
O In-out catheter	
O Sterilising solution	
Dressings	
) Syringes	
Needles	
) Testing sticks	
) Topicals	
Pressure stockings	
) Oxygen	
Suction	
) Feeds	
PEG device	
C Tracheostomy equipment	
) Swabs	
Sensodyne toothpaste	
Thickener (for drinks)	
) Other, please list:	

## Appendix D Equipment checklist

This is a list of equipment that you may use or consider using in the future. For each of the items that you currently use, tick the box. Have a think about any issues or concerns you may have about your equipment for the future.

Item	l currently use this item	I would like to use this item	Notes on my equipment (e.g. works well, needs to be replaced, I would like to have this)
Intrathecal pumps	0	0	
Shower trolley	$\bigcirc$	$\bigcirc$	
Shower chair	$\bigcirc$	$\bigcirc$	
Continence equipment	$\bigcirc$	$\bigcirc$	
Hoist (ceiling or portable)	0	0	
Wheelchair (manual or motorised)	0	0	
Mobility aid (e.g. walker)	0	0	
Specialised seating	0	0	
Personal care equipment (e.g. cutlery; lidded cups)	0	0	
Bed	0	0	
Pressure care mattress & overlays	0	0	
Handrails	0	0	
Environmental control unit	0	0	
Other, please list:	0		
	0		

# **Appendix E** Checklist for choosing supported accommodation

Questions to consider	House 1	House 2	House 3
What are my first impressions?	○ Good ○ Average ○ Poor	○ Good ○ Average ○ Poor	<ul><li>◯ Good</li><li>◯ Average</li><li>◯ Poor</li></ul>
What services are provided? Do they meet my needs?	○ Yes ○ No	○ Yes ○ No	○ Yes ○ No
What are the fees and charges? Does the house offer good value for money?	○ Yes ○ No	○ Yes ○ No	○ Yes ○ No
Are there additional charges on top of the usual fees?	◯ Yes ◯ No	◯ Yes ◯ No	◯ Yes ◯ No
Does there appear to be adequate staff available in the house?	◯ Yes ◯ No	○ Yes ○ No	○ Yes ○ No
Are there activities offered regularly that are of interest?	○ Yes ○ No	○ Yes ○ No	○ Yes ○ No
Do existing residents access external health and other services?	◯ Yes ◯ No	○ Yes ○ No	◯ Yes ◯ No
Do meals appear to be varied and nutritious?	◯ Yes ◯ No	◯ Yes ◯ No	◯ Yes ◯ No
Is the house clean and tidy?	◯ Yes ◯ No	◯ Yes ◯ No	◯ Yes ◯ No
What are the arrangements if I need to be away from the house for a period of time? Does this suit me?	○ Yes ○ No	○ Yes ○ No	○ Yes ○ No
What are the grounds and length of notice if the proprietor wishes to terminate my residency? Does this suit me?	○ Yes ○ No	○ Yes ○ No	○ Yes ○ No
What are the policies relating to smoking, alcohol & other drugs? Does this suit me?	○ Yes ○ No	○ Yes ○ No	○ Yes ○ No
First impressions are always important—rely on your common sense and ask lots of questions.

Questions to consider	House 1	House 2	House 3
Does the house have a home-like environment?	◯ Yes ◯ No	◯ Yes ◯ No	◯ Yes ◯ No
Is there enough space for my belongings?	◯ Yes ◯ No	◯ Yes ◯ No	◯ Yes ◯ No
Are residents' needs for privacy catered for?	◯ Yes ◯ No	◯ Yes ◯ No	◯ Yes ◯ No
Is there a written policy relating to visitors?	◯ Yes ◯ No	◯ Yes ◯ No	◯ Yes ◯ No
Is the temperature comfortable?	◯ Yes ◯ No	◯ Yes ◯ No	◯ Yes ◯ No
Is the lighting and ventilation appropriate?	◯ Yes ◯ No	◯ Yes ◯ No	◯ Yes ◯ No
Is there an outdoor sitting area?	◯ Yes ◯ No	◯ Yes ◯ No	◯ Yes ◯ No
Are there areas for family and friends to get together?	◯ Yes ◯ No	◯ Yes ◯ No	◯ Yes ◯ No
Do staff appear to treat residents and their visitors with respect?	○ Yes ○ No	○ Yes ○ No	○ Yes ○ No
Are my questions received positively?	◯ Yes ◯ No	◯ Yes ◯ No	◯ Yes ◯ No
Is there written information for prospective residents? Is there a residential statement?	◯ Yes ◯ No	○ Yes ○ No	○ Yes ○ No
Would I live in this house?	◯ Yes ◯ No	◯ Yes ◯ No	◯ Yes ◯ No

6. Adapted from Winkler, D., Sloan, S., and Callaway, L. (2007).

### Appendix F Transition checklist

#### 6 - 12 months prior to moving

$\bigcirc$	Start writing an individualised daily care plan for things such as your personal care regime, monitoring and prevention of secondary
	conditions, bowel regimes, PEG feed (enteral care)

- Investigate and trial local community groups/activities
- $\bigcirc$  Apply for additional funding such as mobility allowance, continence allowance, Assisted Community Living packages
- Purchase specialised equipment and furniture
- Arrange home modifications such as plans, permits and builders
- Finalise support model
- $\bigcirc$  Select service providers such as attendant care company, case manager, allied health staff
- Notify friends and family of impending move
- O Delegate jobs to family, friends, team members
- igodot If a funding body is involved, provide the funding body with reports regarding needs and costs associated with move

#### 3 - 6 months prior to moving

- Apply for rent assistance
- Arrange to visit new accommodation

#### 1 - 3 months prior to moving

- Book removal van
- Identify and refer to local services (e.g. pharmacist, GP, optician, podiatrist, dentist)
- Purchase household items (e.g. linen, crockery cutlery etc.)
- Arrange additional support for move/transition
- Arrange additional support services (e.g. cleaner, gardener etc)

Arrange transport e.g. apply for half price taxi card, disabled parking permit, identify suitable local taxi drivers/ maxi taxi drivers, obtain information about local public transport

1 - 4	- 4 weeks before move		
$\bigcirc$	If required, finalise a written care plan and guidelines		
$\bigcirc$	Organise purchase or supply of consumables such as continence aids		
$\bigcirc$	Employ/engage support workers		
$\bigcirc$	Provide training to support workers		
$\bigcirc$	Send new contact details to friends and family		
$\bigcirc$	Arrange delivery of furniture/equipment		
$\bigcirc$	Commence sorting and packing		
$\bigcirc$	Arrange weekly timetable		
$\bigcirc$	Set up cognitive aids (e.g. whiteboards)		
$\bigcirc$	Arrange prescriptions/medications and instructions for administration and webster pack for first week if required		
$\bigcirc$	List of all future appointments and relevant contact details (e.g. specialists)		
$\bigcirc$	Audit and name any of your own equipment that you will take with you		
$\bigcirc$	Document contact details and process for funding the repair and maintenance of equipment		
$\bigcirc$	Obtain mobile phone		
$\bigcirc$	Set up security system (e.g. Vital Call)		
$\bigcirc$	Arrange cleaning		
$\bigcirc$	Get carpets cleaned		
$\bigcirc$	Purchase food to stock pantry		
$\bigcirc$	Water		
$\bigcirc$	Gas		
$\bigcirc$	Electricity		
$\bigcirc$	Telephone		

○ Get locks changed

○ Get keys cut

Provide new contact details to all relevant bodies (e.g. electoral role, Medicare, pension, companion card, bank, utilties etc.)

O If applicable, ensure copies of guardianship and administration orders have been provided to the support provider.

Consider whether you would like to use strategies to meet your new neighbours (e.g. a friendly letter of introduction sent to neighbours; planning an "open house" invitation for neighbours to visit on a set date/time)

6.. Adapted from Winkler, D., Sloan, S., and Callaway, L. (2007).

#### Information and resources

#### **Summer Foundation**

Established in 2006, the Summer Foundation is committed to growing a movement that will resolve the issue of young people living in nursing homes. Supporting, informing and empowering people with disability and their families is key to resolving this issue. You will find useful resources and a copy of this toolkit on the website.

www.summerfoundation.org.au/housingtoolkit

#### DisabilityCare Australia, a national disability insurance scheme

For the latest information about the progress of the scheme, please visit the website listed below.

www.disabilitycareaustralia.gov.au

#### Circles of Support

A circle of support is a group of people who meet together to give support and friendship to a person. The people in a circle should know and care about the person who needs support. A group of people find it easier to sort things out together than someone on their own. They may have new ideas.

www.resourcingfamilies.org.au/index.php/building-support-networks.html

#### **Commonwealth Financial Counseling**

The Financial Management Program is a free service that aims to build financial resilience and well-being for vulnerable people and those most at risk of financial and social exclusion and disadvantage.

www.fahcsia.gov.au/our-responsibilities/communities-and-vulnerablepeople/programs-services/commonwealth-financial-counselling-cfc

#### **Financial Information Service**

A free service to assist you in making informed financial decisions and understand the consequences of these decisions

www.humanservices.gov.au/customer/centrelink/financial-informationservice

#### Managing your Money

The MoneySmart website is run by the Australian Securities and Investments Commission (ASIC) to help people make smart choices about their personal finances.

https://www.moneysmart.gov.au/tools-and-resources/publications

#### Superannuation

The Super Future website provides up to date information on issues to do with superannuation

http://superfuture.gov.au/

#### Preparing a Will

The Intellectual Disability Rights Service has developed this resource to assist individuals and families with preparing a Will.

http://www.idrs.org.au/pdf/factsheets/factsheet\_will\_for\_parents.pdf

#### **Disability Parking Scheme**

Provides people with a disability with access to parking permits, to ensure easier access to a range of venues.

www.disabilityparking.gov.au

#### RampUp

RampUp is a website produced by the ABC with assistance from the Department of Families, Housing, Community Services and Indigenous Affairs, that features disability related news from across the ABC.

www.abc.net.au/rampup

## References

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# 

## Introduction

This booklet provides information to people with disability and their families about a range of housing and support options so that they can make choices about their future housing and support.

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) states that all people with a disability should have the "opportunity to choose their residence and where and with whom they live on an equal basis with others, and not be obliged to live in particular living arrangements". The Australian Government ratified this convention in July 2008. However, there is still much to be done to fulfill the obligations agreed to in the United Nations CRPD, especially for people who require access to 24-hour support.

Some people and their support network will already be interested in exploring different housing and support options. However, many people will find it difficult to imagine living anywhere other than their current living situation, and may not have any knowledge about the range of housing options that can be developed for people with disability.

Following are some examples of housing and support options that some people have chosen. This resource is designed to help you think about what housing and support option would be ideal for your lifestyle, preferences and needs.

## Developing accommodation & support models

Achieving a successful housing and support solution is an involved process. Developing a housing and support solution with people with disability requires an understanding of the person's support needs, and consideration and planning for the most successful way of meeting those needs. The Housing Toolkit, available on the Summer Foundation website, can assist with this planning. (*www.summerfoundation.org.au/housingtoolkit*)

Here are some points to consider in developing housing and support options as well as information about some of the models that other people are currently utilising.

#### **Developing a support model**

The essential starting point is to develop a detailed understanding of the person's goals, needs and interests, and then select and structure an appropriate living environment as well as a support model that will best meet the individual's needs. Even when you can identify an existing housing option, you will need to tailor or fine tune the support structure and living environment to meet the person's specific needs and goals.

#### In general, the following principles apply

- Start by working out the person's broad support needs (e.g. 24 hour care/active or inactive overnight care/able to be left alone for some of the day, and if so when)
- Identify the essential factors that are necessary to enable the person's key goals and support needs to be met. Ensure the solution addresses the essential factors and as many of the less essential or optional factors as possible. The person and their family have to make some compromises and this will require a degree of problem solving.
- Work from the general to the specific (e.g. start with the broad geographical location and narrow it down; start with a general idea of who the person is most suited to live with, and then narrow it down to specific individuals the person might like to live with).
- Match the person's support needs to that offered by potential environments. Consider ways to compliment the support provided or fill gaps in support (e.g. with other paid or gratuitous support / specialist services).
- Understand and build in ways for the support model to be *adapted* to the person's changing needs (e.g. allow for the person progressing in their skills)
- Ensure that the option:
  - is acceptable to the person and the support network, and based on their goals and aspirations
  - meets needs and ensures safety and dignity
  - maximises independence and opportunity
  - is sustainable over time

#### **Structuring Support**

The below illustrate ways in which aspects of the support model can be problem-solved. On the left is a list of questions to answer in order to arrive at an understanding of the type and amount of support required.

Understanding a person's support needs helps to decide on the housing and support model within which this support can be delivered. It is important to consider the full range of personal, domestic, community, work and recreation activities the person participates in across the week. Different activities will probably require different amounts and types of support, which dictates the development of a flexible model of support.

What support does the person need?	Help with showering		
Why do they need it?	Balance and mobility issues		
When do they need support?	In the morning		
Where is the support to be given?	In the individual's bathroom		
Who will deliver the support?	Personal care worker in group home employed for a 2 hour shift (in addition to shared support)		
How will they deliver it?	1:1 supervision and hands-on help to transfer		
What support does the person need?	Help with problem solving unfamiliar situations		
Why do they need it?	Executive (thinking) function difficulties relating to ABI		
When do they need support?	Incidentally throughout the week when unexpected situations arise		
Where is the support to be given?	Via telephone or in person, depending upon availability of support person		
Who will deliver the support?	Parent		
How will they deliver it?	Verbally, followed up with written step-by-step instructions depending upon complexity of issue		
What support does the person need?	Hoist transfers from bed to wheelchair with assistance of 2 people transfers from bed to wheelchair with assistance of 2 people		
Why do they need it?	Physical mobility issues		
When do they need support?	Morning personal care, lunchtime for return to bed for rest, 2pm return to chair, after dinner to return to bed		
Where is the support to be given?	Individual's bathroom and bedroom		
Who will deliver the support?	Parent and attendant care worker		
How will they deliver it?	Hands-on help of both people		
What support does the person need?	Cognitive support		
Why do they need it?	Prompting for leaving the house with wallet and keys etc		
When do they need support?	Every time they leave the house		
Where is the support to be given?	At the main entrance to the house		
Who will deliver the support?	The Occupational Therapist to set up the strategies for the individual to self-prompt		
How will they deliver it?	A checklist of things to take and a prompt to look at this list posted at the front door		

# Living in the family home

**John & Louise's story** Five years ago, John was riding his bike to work when he suffered a bleed from an aneurysm which resulted in a severe brain injury. At the time of the injury, John and Louise were engaged, were working hard to pay off their lovely terrace home and had a busy social life. John survived, but was left severely physically disabled and confined to a nursing home.



John has a very high level of disability and can only move his head a few centimetres. He also has profound memory loss and is unable to remember events from hour to hour. So, he is totally dependent on others to assist him with everyday activities and requires 24hour support with someone on call overnight.

From the start, Louise was determined to bring John home. But she met a lot of resistance from health professionals, family and friends who thought her plan was unrealistic. Although she found it a huge learning curve to understand John's brain injury, care needs and the equipment and supports he would require to live at home, Louise persevered.

They were married when John was still living in a nursing home. Preparing for the move home required persistence, planning and hard work to put everything in place. Now with the help of a wonderful team of disability support workers, the couple are living together in their home.

Today John participates in a range of home-based activities and is a regular at the Irish Club. John gets 44 hours of paid care which enables Louise to study nursing. They also receive ongoing assistance from a case manager, occupational therapist, speech pathologist, the Aids & Equipment Program and a continence subsidy program. Louise continues to provide a high level of unpaid care to John each day, however both John and Louise are thrilled that they are together again.

John and Louise's story was first printed in *From a* Home to their homes. Alternatives to young people living in nursing homes (2007), Summer Foundation Ltd

#### About living alone with support

All of us start out living with family in our early years. Then, as we grow up and move out of the family home, we pick up the skills required to live independently. But some people acquire a disability before they have had a chance to learn these skills or experience living on their own or with friends.

On the other hand, there are those who became injured after they had experienced independent living and who consequently have more fixed expectations about independent living.

There are different challenges and considerations for those who are thinking of pursuing the option of living with family.

For some, it provides a transition from hospital or residential aged care to more independent living; for others it will become a more permanent accommodation option. Either way, living in the family home will require family members to provide an on-going level of care to their disabled relative, and may require them to accept a steady stream of external care providers, such as disability support workers.

Living with family may not literally mean re-entering the family home. There are many other possibilities such as extending the home to provide self-contained accommodation, building a bungalow, or placing a moveable unit on the family property for the individual.

These options may offer increased privacy and independence to both the individual and the family. Although there is the risk that a separate living area will become an extension of the family home and thus reduce privacy, though this is less likely to happen with a bungalow. An intercom between the family home and the person's living area may maintain privacy whilst still offering support.

#### Pros and cons of living with family

- May provide more consistent, dedicated and flexible care
- Offers familiarity with physical and social environments
- May rely on a high level of care by family members
- Not as costly as other support options (due to sharing accommodation and living costs and reliance on care by family members)
- May impact upon family relationships
- Risk of the family limiting the individual's lifestyle choices (e.g. risk taking, friendship groups)
- Risk of role confusion (e.g. partner/parent or caregiver?)
- Increased demands on family with accompanying stress and caregiver burden
- Reduced privacy of other family members when paid carers and therapists work in the family home
- May not be viable in the long term when, for example, parent caregivers get old or ill

# Living in your own home close to shared support

**Mark's Story** Six years ago, a car accident left Mark with a badly broken body and severe brain injury. After many months of rehabilitation he returned to live with his parents, and then moved to a group home with shared support. But Mark found it difficult to live with other people; he wanted to live by himself.



Initially, his family and support workers were unsure whether he'd be able to manage on his own. Mark moved into a small house, around the corner from the group home that he had lived in, which gave him privacy and his own space. It also had 24 hour on-call support available from disability support workers in the group home.

Now Mark has developed a morning routine of going to the group home to get his medication, and then taking one of the residents out for coffee at a local café. But he's not entirely left to his own devices. Every week support workers give him 11 hours of assistance with integrating into the community, and each evening a support worker visits for an hour or two to help him with domestic tasks.

Mark is lucky enough to have a very supportive family and he speaks to his mother and brother most days. He also has ongoing support from a Neuropsychologist to help him manage his challenging behaviour and an occupational therapist to help him become more independent in managing his domestic and community tasks.

Mark's story was first printed in From a Home to their homes. Alternatives to young people living in nursing homes (2007), Summer Foundation Ltd

#### About living alone with support

Although many people with a disability would love to live on their own without any support, it is not always possible or practical. But it often is possible to integrate the support required into daily life and direct it towards helping with specific everyday tasks and activities.

There are a number of ways of getting this support.

Sometimes it can be provided by family members or significant others. Alternatively it can be paid for, and most commonly provided by disability support workers. However some people are not keen on the idea of paid carer support, so another alternative is to get 'normalised' assistance in the form of a cleaner or gardener or personal assistant etc. Quite often people will use a combination of these different methods of support.

The level of support can be varied according to the needs of the individual. Some may want direct, one-on-one supervision and assistance 24-hours a day; others may only need weekly phone contact and occasions visits. There are also many options in between.

Another important consideration that requires planning is the physical environment of the house, apartment or unit in which the person chooses to live. The accommodation should be tailored to meet the needs of the individual. All kinds of things need to be thought about: for example the number of bedrooms, size of garden, facilities for pursuing hobbies (e.g. shed for woodwork), level of home maintenance, required accessibility, room for carer accommodation and space for entertaining.

#### Pros and cons of living alone with support

- Potential for more choice and control over everyday decision-making and the opportunity to direct one's own care
- Greater opportunity for lifestyle choices
- Homemaking can provide opportunities for meaningful, productive occupation
- Living alone, with or without home ownership, may provide a sense of achievement
- Offers tailored support which can be modified over time as support needs change
- May be cost effective if support needs are low; but can be very expensive for people who have high support needs
- Often the most expensive option as the individual would incur all care-related expenses rather than being able to share costs with co-residents
- 24 hour support programs require a high degree of input to establish and maintain, and require extensive coordination
- The person is potentially quite vulnerable and it is vital that ongoing monitoring and crisis support is factored into the support program
- Whilst some people enjoy time alone and value the opportunity of making their own friends, others may experience social isolation when living alone

# Living in an apartment

**Amidu's story** Amidu and his family emigrated from Ghana to start a new life in Australia. A committed family man, Amidu worked hard as a taxi driver to support his young family. One day while working Amidu suffered a stroke, a life-changing event for he and his family.

After a long stay in hospital, Amidu moved back to the family home. However Amidu's care needs were too much for his young family to manage, so he moved into a nursing home a year later. Quickly Amidu knew that a nursing home was not the place for him. During the five years living in the nursing home, he became isolated and withdrawn. Amidu wanted to live in a place where is children would feel comfortable visiting and where he could continue to be a parent to his children. This is one of the most important reasons that drives Amidu's pursuit for independence.

With the support of his Case Manager, Amidu began planning to live independently. He continued to work on his living skills, again learning to talk and eat by himself. After eight months of planning, Amidu moved into his own apartment. The apartment has been modified to allow Amidu to do household tasks such as his own washing and meal preparation. Support workers visit for an hour each morning and evening. Living alone and receiving a small number of support hours, there is often a risk that Amidu will have to wait for support or that his support may not arrive at all. This is a risk that Amidu is willing to take in order to be able to live independently. A keen follower of Aussie Rules football, Amidu regularly attends footy games to watch his beloved Carlton team play. He attends hydrotherapy three times a week and each morning lifts hand weights to improve his mobility. He enjoys trips to his local shopping centre to buy his own groceries and attends a men's group each week. Living in his own apartment has given Amidu the freedom to be active in the community. His next goal is to stand on his own and not rely solely on his wheelchair to get around.

For Amidu the most important part of this journey has been finding a place of his own to share with his children.

#### About living in an apartment

For many people with disability, living independently is the ultimate goal. Whilst there are challenges to be overcome, for some people it is possible to develop a model of support that combine independence and support.

The level of support required will be different for each individual. Depending on the level of financial support or resources, people may need to seek support from friends or family members. There are people who would like access to support 24-hour per day and others who would prefer minimal support from paid carers. A significant amount of thought and planning is required to ensure a good outcome. To ensure independence, the apartment needs to be modified so that the physical environment meets the needs of the individual. You may need to consider the height of kitchen benches, storage space for equipment, the number of bedrooms and space for visitors.

#### Pros and cons of living in an apartment

- The cost of rent or purchase price of an apartment is less than a stand-alone property
- There can be a sense of community in an apartment block particularly if there is a communal garden area
- Living alone provides a sense of control and choice for everyday decision making
- Can be cost effective for people with minimal support needs
- There is a sense of achievement with living in and creating your own home
- Storage space may be an issue, particularly if you utilise large pieces of equipment and use continence products
- The risk of having limited support hours must be considered, as you may be alone without assistance for extended periods of time
- Can be vulnerable in a larger complex; thefts of property in outdoor spaces on the ground floor can occur
- This option can be expensive for people with high support needs
- Will incur all the costs of support rather than being able to share costs with co-residents.







# Living in a moveable unit or bungalow

**Davina's story** Twenty-three years ago, Davina was involved in a motor vehicle accident, sustaining a severe brain injury. Although Davina had previously lived out of the family home, at the time of the accident she was living with her parents. After the accident and a period of rehabilitation, Davina returned home to live with her parents in the outer suburbs of Melbourne. As her family had only moved into that particular house in the months prior to her accident, Davina did not recall ever having lived there.



Davina has always been very independent, and she knew that she did not want to stay living with her parents in the long term. There were two key factors that shaped Davina's goals for future housing: she did not wish to share accommodation with other people, and she did not want to receive attendant care support for daily tasks. As a result, Davina and her family decided to purchase a transportable unit, which was initially situated on the family property in Melbourne.

A moveable unit was selected as it assisted long-term planning for Davina's future when her parents would no longer be able to provide support. The ability to move the unit meant that her familiarisation with her home environment could be easily transportable to a new location if needed. This was particularly important for Davina as she has experienced issues with memory following her accident. A key element of this model was an intercom system between Davina's moveable unit and the family home, so that Davina could contact her parents if she she needed help. A few years ago, when Davina's parents decided to sell the family home, Davina decided that she would like to live in a small coastal town, where she had taken caravanning holidays with her family for many years. Davina identified a number of advantages to this location, including her familiarity with the local area, having existing social contacts and interests in the town, the friendly nature of the community, and the close proximity to the beach and local shops.

Davina first purchased a property in this town, on which she could relocate her unit, and after some time Davina's parents built a unit at the front, with Davina's moveable unit located on the rear of the property. Davina says that her mobile phone, which she keeps on a lanyard around her neck, is key to ensuring she has the help she would like, when she needs it.

Davina really likes the flexibility of being able to visit her parents, or spend time in her own unit with her dog. She makes the most of living on the coast, enjoying swimming, cycling, kayaking and walking along the beach. Davina has once again has achieved a level of independent living that she is satisfied with.

#### About living in a moveable unit

Often the first step in moving out of the family home can be daunting, particularly when support has been available to a person by living with family. A moveable unit, particularly when placed on the same land as the family home, offers the opportunity to test out more independent living whilst still remaining in very close proximity to key support networks. Moveable units also offer the capacity to be relocated to other geographical locations as circumstances change, whilst continuing to offer the stability of a well-learned living environment within the unit itself.

This booklet has detailed previously the range and possible combinations of support a person may receive for community living, including assistance from family members, disability support workers, or more 'normalised' assistance in the form of a cleaner or gardener. The use of mainstream and other customised technologies, such as an intercom system, mobile phone or tablet technology can allow a person to live with maximum independence whilst having access to on-call support of another person living on the same block of land or in the local area. All of these support options should be considered when planning for living in a moveable unit, with the final options utilised based on the needs and wants of the person living in the unit, and their support network.

#### Pros and cons of living in a moveable unit

- An opportunity to test out more independent living whilst also having family or others in close proximity
- The capacity to become very familiar and learn living skills with one home environment and retain that familiarity even if the unit is moved across geographical locations
- Requires the person to have access to land upon which to place the unit
- Units tend to be restricted to one, two or three small room units, thus do not offer large family spaces for a number of people
- If the unit is placed on land with another property already built on that land, planning and consideration must be given to what happens if ownership or tenancy of the other property changes, and how that may impact the capacity to retain the moveable unit on that block of land
- May require the outlay of capital funds to purchase the moveable unit, although some state governments do provide low cost rental (e.g. Victoria's Department of Human Services moveable unit program)
- There are costs involved in transporting a unit to a new site if it is to be moved, as well as having unit plumbing, water and electricity connected at the new site. The larger the unit, the greater these costs may be.

# Living in shared housing with people without disabilities

**Matthew's Story** Matthew was a 19 year old university student when he suffered a severe traumatic brain injury. Due to the severity of his cognitive-behaviour impairments, his support needs were very high and his family was told that he would need to remain in a locked facility indefinitely. Matthew required 24 hour supervision however, shared supported accommodation services were not an option because one of the key triggers for his challenging behaviour was his dislike of living with other people with disabilities.



Prior to his injury Matthew had a wide circle of friends and his interpersonal skills and his capacity for relationship are still his key strengths. Matthew responded much better in a normalised environment. Supported strongly by his family, Matthew's rehabilitation team developed a model of community living specifically to meet his needs. Given Matthew's profound memory difficulties it was critical that Matthew live in a local area that was familiar to him prior to his injury. At age 23 Matthew moved out of the locked facility to a home shared with non-disabled tenants. In return for subsidised rent, Matthew's housemates assisted by providing him with friendship, a positive social environment, general supervision and shared direct assistance each evening.

The arrangement has proved a great success for over ten years. Matthew is now extremely reliable in many tasks. He helps out around the house and participates in community activities such as banking and shopping. He has a structured program of leisure and avocational activities, and systems are in place to assist Matthew in maintaining his friendship group. He is also better able to occupy his own time for short periods, and as a result his attendant care hours have been reduced, and he no longer requires 24 hour supervision.

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Matthew loves walking along his local shopping strip, where he is a familiar face to many, and he enjoys the independence of visiting cafes as well as travelling on the train, in the company of others, which is one of his favourite pastimes.

#### About living alone with support

While shared supported accommodation services suit some people with disabilities, there are many people with acquired brain injury who are not able to successfully live with other people with disabilities. Shared living with other people is common for some in the general population such as university students and young professionals.

#### Pros and cons of shared

#### housing with people without disabilities

- This individualised approach enables the person to live in a familiar suburban setting
- Provides a social living environment for people who seek a lot of social contact
- Housemates can provide positive social role models for people with disabilities who are working on their social skills
- This model takes an enormous amount of time and energy to set up and maintain over time
- Careful recruitment and training of housemates is critical for the success of this model

## Living in a cluster of units

**Byron's Story** Byron sustained a severe brain injury, which has left him with limited physical abilities so that he relies on the support of others to complete everyday activities such as meal preparation and shopping. When Byron left the rehabilitation facility he gave consideration to living in shared supported accommodation or a cluster of units. For Byron it was an easy choice, as he was keen to purchase his own unit and have his own space.

Byron shares support with three other people who live in the units adjacent to his. Disability support workers come by to assist him at meal times. Byron keeps his phone with him at all times so that he can press 9 and obtain assistance in the event of a fall or other urgent matter. Byron also has 13 hours per week of attendant care to assist him to participate in community based activities such as shopping, going to the gym and going to the football every second weekend. Byron is also a regular at some social groups in the evening and a woodwork group run by a local disability service.

Byron enjoys the privacy of having his own unit, particularly when he has visitors. He likes the security of owning his own unit. However, like many people who have an acquired brain injury he does not have as many people visiting as he would like. Byron has little or no contact with his friends from before his injury. He doesn't have any social contact with the other people in the cluster of units. He depends on his attendant care program and the three groups he attends for his social contact. Without these groups and the support of his mother he is at risk of becoming very socially isolated.

#### About clusters of units

This is an environment where a number of people live independently but in close proximity to others who require similar levels of support. For example, they might all live in the same block of units or in flats at the back of a shared supported accommodation facility.

These cluster settings may offer a centralised, funded service that provides flexible shared support to a group of people living the same area. Occupants may purchase or rent their own unit and are able to access 24-hour shared attendant care support. They also receive varying levels of 1:1 attendant care to help them with specific activities as part of daily living.





#### Pros and cons of clusters of units

- Provide pleasant living environments in suburban settings
- Offer opportunities to participate in a wide range of domestic and community activities
- Provide privacy as well as opportunities for social contact with others in the units and the local community
- Generally good staff-to-resident ratio for people with moderately high-level needs
- Staff may have experience, or be offered training in managing people with specific disability types (e.g. acquired brain injury, MS, Huntington's Disease)
- May not be suitable for those with very highneeds (e.g. if intensive nursing care or a secure environment is required). However the person may be able to obtain additional one-to-one support in addition to shared staffing
- Clusters of units may not exist in the person's preferred location
- Many people prefer to live alone or may not be agreeable to living near other people with disabilities
- There may be a mixture of disability types and ages resulting in very different support needs
- Varying opportunities to personalise living environment and the structure of support

# Living in a high care facility for young people

**Gayle's Story** In 1988 Gayle was in a car accident and suffered a severe brain injury, which forced her to spend years in hospitals and rehabilitation centres. She requires 24-hour supervision and assistance with some everyday activities.

Today, Gayle lives in a shared accommodation facility, which is home to 15 residents between the ages of 25 and 65. This facility has a higher level of care and a more institutional feel to it than the other options described in this booklet. Over the years, Gayle has been offered the chance to try more independent living, but she's content where she is. She particularly enjoys all the opportunities that the facility offers for social interaction and making friends. If at times she finds it difficult to get along with the other residents, it's always easy to go outside or retreat to her room.

It's a friendly environment where she feels at home and, for Gayle, the balance is right. She has the independence she wants, and the assistance she needs, available 24 hours a day.



Gayle's story was first printed in From a Home to their homes. Alternatives to young people living in nursing homes (2007), Summer Foundation Ltd

#### About high care facilities for younger people

There are organisations for specific disabilities that have developed their own care accommodation. These include the Arthur Preston Centre (Huntington's Disease), Cyril Jewell House (Multiple Sclerosis) and Glenhaven (ABI).

Typically these facilities have 15 to 30 residents and have expertise in supporting a specific disability group. Sometimes the facility can cater for changing needs, for example the progression to higher levels of care in the case of Huntington's or MS, or the facilitation of greater levels of independence in the case of ABI.

Current disability policy supports the development of smaller scale housing that is more home-like and less institutional. But this may not suit everyone. Many younger people who have spent many years in residential aged care feel more secure in a "younger persons' nursing home". Sometimes a home such as this may be a stepping-stone to more independent living. Over the years, many people who have lived in a high care facility have moved on to living in a group home, a cluster of units or their own unit.

#### Pros and cons of high care facilities for younger people

- Can meet the high care needs of specific disabilities
- Although still institutional in nature, a broader range of needs may be met
- Staff may have expertise in acquired or late onset disability
- Limited opportunities to match people of compatible age, interests and other factors
- May be located well away from the person's local area and social networks





# Living in shared supported accommodation

**Anne's Story** Twenty years ago, Anne was studying outdoor education and looking forward to a bright future, when she was struck by a car while riding her motorcycle.



In the course of living in a nursing home followed by a long stay in hospital, Anne worked hard on regaining her independent living skills. The work paid off and eventually she moved into her own unit where she lived by herself for a few years. It was a major achievement, but as time went by Anne discovered that living by herself was not right for her; she found it lonely and challenging, and moved into a shared supported accommodation where she has now lived for the past few years.

Now she lives with three other people in the home which is located next to a facility for people with disabilities. Support workers are on hand during the day, and should assistance be required overnight, the support workers from the facility next door can come over.

Anne thoroughly enjoys her independence and the opportunity to get involved in the local community. She is a regular at the local market, sits on a committee at the local council and does volunteer work. But while the social side of communal living is fantastic, some of the inevitable rules associated with communal living can be frustrating at times. For example, she has her own cat but it is not allowed in the house during the day.

For Anne it has been a worthwhile journey. In the beginning, she thought a nursing home would be her only option; but with a little help and a lot of perseverance she has now taken control of her life.

#### About shared supported accommodation

A number of shared supported accommodation facilities have been established across Australia, and are now run by either private or public-funded disability services. They are usually set up to offer long-term placement and don't usually incorporate rehabilitation services. However, most have the flexibility to accommodate at least some of the needs of each individual resident.

#### Pros and cons of group homes

- Provide pleasant living environments in suburban setting
- Offer opportunities to participate in a wide range of domestic and community activities
- Provide opportunities for social contact with others in the home or local community
- Generally have a good staff-to-resident ratio for people with moderately high level needs
- Staff may have experience, or be offered training in managing people with specific disability types (e.g. acquired brain injury, MS, Huntington's Disease)
- May not be suitable for very high-needs individuals (e.g. if intensive nursing care is required or wandering is an issue). However the person may be able to obtain a high level of one-to one support in addition to normal staffing levels

- There are limited vacancies in many shared supported accommodation facilities due to high demand and low turn over
- Group homes may not exist in the individual's preferred location
- Many people prefer to live alone or may not be agreeable to sharing with other people with disabilities
- Often there is little opportunity for selecting housemates on the basis of compatibility
- There may be a mixture of disability types and ages resulting in very different support needs
- Varying opportunities to personalise the living environment and the structure of support

# Living part-time in shared supported accommodation

**Peter & Grainne's Story** Peter and Grainne had been married for 2 years when Peter sustained a severe brain injury in a car accident in 1987. The injury left him with a high physical disability level and he requires 24-hour support and assistance with most everyday activities.

Peter lived for years in a long stay hospital prior to moving into shared supported accommodation where he shares support with three other people. Since Peter's accident, he has always lived at the family home on the weekends.

Over the years Grainne has had pressure from various health professionals to stop work and take Peter home full-time. However she has resisted it, and maintains that the best thing for their marriage is for Peter to live in supported care during the week and at home on the weekend. Grainne visits Peter every evening during the week and takes him home from Friday night to Sunday night. It's an arrangement that allows both of them to maintain balance in their lives.





Peter and Grainne's story was first printed in *From* a Home to their homes. Alternatives to young people living in nursing homes (2007), Summer Foundation Ltd

#### About living part-time in shared supported accommodation

Some families are keen to be actively involved in the care and the life of a disabled partner or relative but find that looking after them 24 hours a day, seven days a week, is too demanding.

Although a part-time arrangement is not common and may be difficult to arrange in terms of staffing and funding, it can be an ideal solution for some families. It's an arrangement that can work in different ways. Some families may want to have the individual at home for the weekends; while others who manage to have them at home during the weekdays, because of the availability of day-time activities, want time off over the weekend.

It might be possible to arrange for a pair of individuals to share occupancy of a bedroom in shared supported accommodation. While one individual used the room during the week, the other would use it on the weekend. It might be difficult to arrange, but would mean that they could live with their families on the other days of the week.

#### Pros and cons of living alone with support

- It may be difficult to find two people who want to live in the same group home on a part time basis
- Storage of equipment, personal items and clothes in one bedroom may be problematic
- Additional resources may be required to change linen and clean the bathroom and equipment between occupants
- Having two part time co-residents may be disruptive to other household members
- This arrangement may enable the family and the individual to maintain some balance in their lives
- This may be a more realistic long term solution than living with family seven days per week



PO Box 208, Blackburn 3130 Victoria Australia

**TELEPHONE** +61 3 9894 7006 **FAX** +61 3 8456 6325 **EMAIL** info@summerfoundation.org.au

www.summerfoundation.org.au