

## What is your life like now?

Your Participant Statement includes information on your day-to-day life. Think about:

- what you participate in such as education, work and social activities
- what is working well in your life
- what you would like to change or improve
- whether there is something new you would like to try (this could be a therapy, an activity in your local community or a volunteer group you would like to join)
- activities you enjoy or you are good at
- what you do when someone comes to help you in your home.

I currently live at home with my husband Neil in our 3 bedroom house. My two daughters have moved out but both of them visit often. I work part-time as an art teacher at the local high school and teach pottery classes on Thursday nights and Sunday afternoons. I enjoy gardening and participate in the local community garden which is located down the end of our street. I enjoy my work and love teaching pottery.

I am a very social person and Neil and I are always having people over for dinner or going out to the theatre or a concert. I am active within my community and like to garden in my spare time. I like to go visit my daughters and my grandson on Saturday afternoons.

I was diagnosed with early onset Alzheimer's last year at the age of 59. While I still remain in the early stages of Dementia I will need to put in place support structures to help me in the future. My husband currently aides in my caring.

My life has changed since my diagnosis as I am unable to drive and have had to cut down to part-time work at the school. I need to rely on Neil to drive me to and from work and to my pottery classes. We currently have no outside help but as my symptoms progress I will need to find people to support me in my everyday life.

I would like to keep my daily life activities and living arrangements as much the same as it is now. I would like to improve my transport so that I don't have to rely on Neil to drive me everywhere and I would like to start putting changes in place to help in the future when my abilities deteriorate.

### Regular activities

Day	What I do	What help I have
Monday	Go to work Alzheimer's Support Group meeting	Neil drives me/picks me up
Tuesday	Go to work	Neil drives me/picks me up
Wednesday	Go to work	Neil drives me/picks me up
Thursday	Work in the garden at home Teach pottery at the local community centre	Neil drives me/picks me up
Friday	Work in the community garden Go out to dinner/theatre/have people over at our place	I need more assistance when having people over with the organisation
Saturday	Visit my grandson in the afternoon	I have to go with Neil as I am unable to drive
Sunday	Work in the community garden Teach pottery at the local community centre	Neil drives me/picks me up

### Occasional activities

Month	What I do / how often	What help I have
January	Once a year trip to the coast	Neil does all the organising for this trip

Use this information to help complete page 2 of your Participant Statement.

### What are your current living arrangements?

Think about:

- who you usually live with
- the type of accommodation you live in

- whether there is something you would like to change about your living arrangements to make things easier for you, or to increase your independence.

I live with my husband Neil in our 3 bedroom house with a big backyard. We have 2 Border Collie dogs named Muppet & Gypsy. Our two daughters moved out of the house about 8 years ago.

I would like to change areas of the house so that I can stay in my current living conditions as long as possible. Examples such as installing sensor lighting, change bathroom fixtures so that they use colour contrast and install safety features such as hot water cut off devices and fall detectors.

Use this information to help complete page 2 of your Participant Statement.

## **What relationships do you have now?**

Think about:

- who is important in your life and in what way
- what informal supports you have from family, friends, or neighbours.

My family is very important to me. I want to play a part in my grandson's upbringing and to be there for my daughters. My husband Neil is extremely important as he is my main provider of care.

My work colleagues and my students play a large part in my life as they keep me challenged in the work environment.

The community members that participate in the community garden are a great support network. They look out for me when I am in the garden and offer me any assistance that I might need.

Use this information to help complete page 2 of your Participant Statement.

## **What supports do you currently have?**

### **Programs and therapies**

Think about:

- specific programs you access, such as those provided by your local council, religious, community or support groups, your hospital or school
- any therapies you require, such as therapeutic support or behaviour support.

I currently attend an Alzheimer's Support Group at the local community hall on Monday nights. This is a great source of support and gives me a chance to talk to other people who have been diagnosed with early onset dementia. This is also great for Neil as he is able to talk to other carers who come along.

Neil and I have also attended a couple of counselling sessions to help with how we can approach the changes that are occurring and how we are both feeling about these changes.

I would like to include speech assessment and therapy to maintain my language which will be affected by my condition. It is very important to me to be social and communication is essential.

### **Aids, equipment or modifications**

Think about:

- any special equipment you have or you need. For example, a wheelchair, hearing or speech aid or hoist. How often do you use this equipment? Is it appropriate for your needs?
- whether your home has been, or needs to be, modified. Do you have or need any ramps or lifts?

I am starting to experience my first difficulties at home and will need modifications to my house to make life easier and to maintain my independence. I want to stay and be safe in my house for as long as possible.

Modifications such as installing sensor lighting, changing bathroom fixtures so that they use colour contrast and installing safety features such as hot water cut off devices and fall detectors will make my home easier and safer to live in.

### **Assistance with activities**

Think about:

- what assistance you have to carry out your day-to-day activities, including participating in work or study, transport, sport, day program or community access, managing money, respite etc.
- what formal supports you have through the health care system, community centres, work or education, cleaners, personal helpers etc.

My primary carer is my husband Neil and he assists in driving me to and from work and my activities throughout the week. As I am starting to find things more difficult at home he assists me more in everyday activities at home. My daughters also help out at home when they can.

I will need more support and assistance in the future with a need for someone to assist me in getting to classes, gardening and my support group.

If Neil gets sick, I will need to find a service that can help me, either a place I can go or for someone to stay with me at home.

Use this information to help you complete pages 4 and 5 of your Participant Statement.

## Your goals

There may be things you want to achieve in the short and longer term.

Think about:

- the supports you already have in place
- if something is stopping you from achieving your goals
- what steps you need to take to get where you want to be.

Use the spaces below to write down your goals in different areas of your life. You don't need to write in every box; just those most important to you.

**Employment** – e.g. would you like to get a job, volunteer or change your work hours?

I would like to try to stay at work for as long as possible. Discussions will need to occur with the school to see if it is possible. I am currently doing part-time hours and would like to continue with this.

I want to continue teaching my pottery class. I will need to be supported in order to continue these pottery classes as I can't rely on Neil to sit with me during these lessons.

**Education** – e.g. would you like to attend school, university or a course?

Not Applicable

**Social participation** – e.g. would you like to join a club, be more able to attend events, see your friends or make new friends?

I want to keep being part of the community garden two times a week. I get a lot of out of the community participation and the other members who help out in the garden make sure that I am ok. As the garden is not always attended, Neil worries that something may go wrong. Someone who could come to the garden and support me would be very helpful.

I want to be able to still be social and go and see my daughters and grandson when I can. Neil is my only access to transport. As he also has activities that he participates in, access to another person or transport to help me in this area would be great.

**Independence** – e.g. would you like to get around the house or community on your own or with less assistance?

I want to continue the independence that I have with the current social and community groups that I participate in. As I am limited in how I can get to and from these events I need to find a solution to transport and having someone support me in these activities.

I want to have some independence from my husband Neil as I want to ensure that he has time to do his own activities. As there are no others that are able to offer the same support as Neil, I need to find someone to offer the same support services as he does without changing my activities dramatically.

**Living arrangements** – e.g. would you like to modify your home or live somewhere different?

I want to modify my home to become safer and to be able to reside for as long as possible with the current arrangements. There needs to be changes in the lighting of the house and having safety measures in place in both the bathroom and kitchen to help with daily activities.

**Health and wellbeing** – e.g. would you like to be more active or take up a sport?

I want to keep being active and being able to work in the community garden. I want to continue with my pottery classes.

I will need to have someone support me with these activities but I feel they are the most helpful in keeping a positive outlook on my diagnosis and having a high quality of life.

Use this information to help complete pages 6-9 of your Participant Statement.