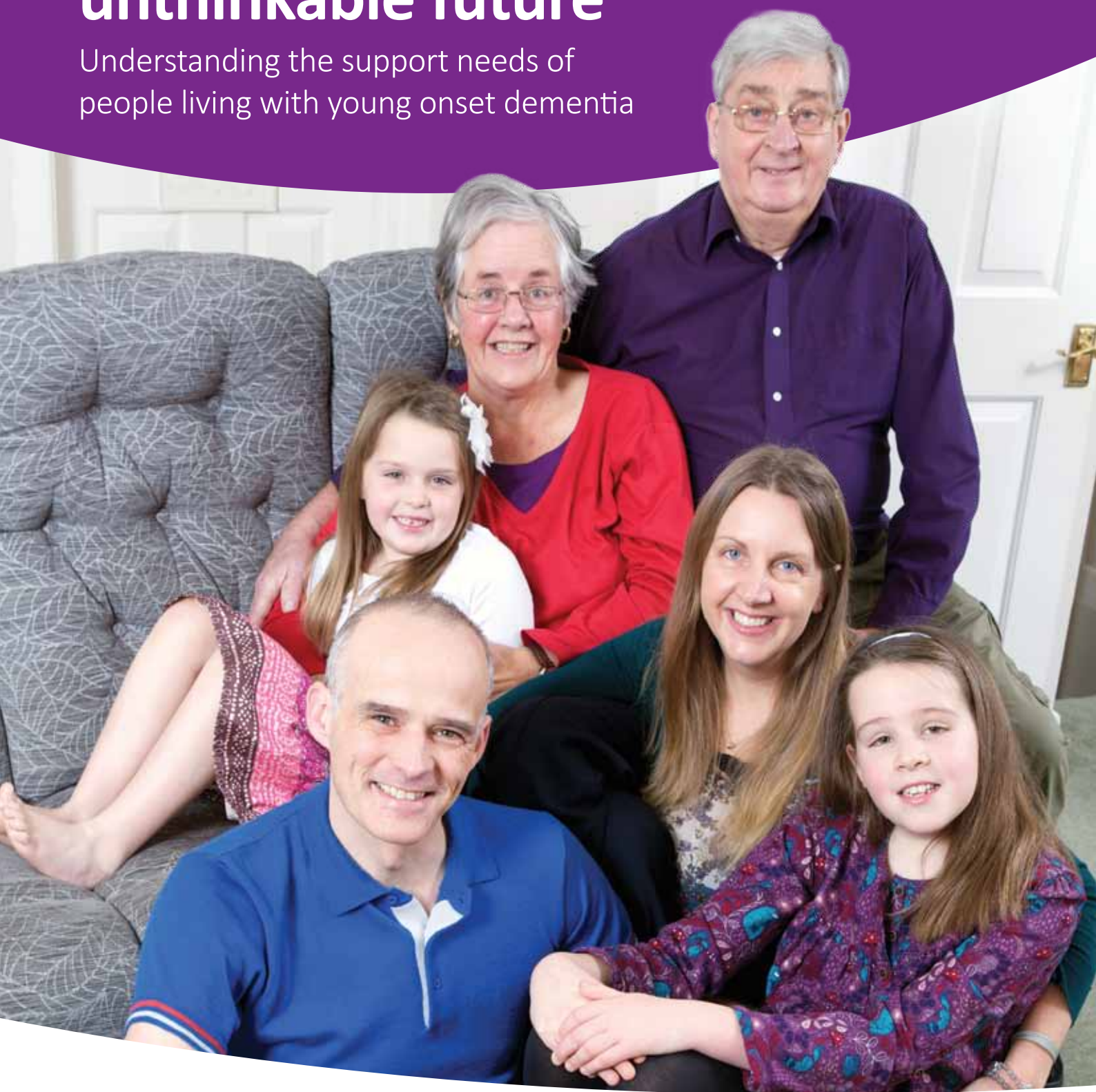



Approaching an unthinkable future

Understanding the support needs of people living with young onset dementia





A resource based on the experiences of people living with young onset dementia contacted by Dementia Pathfinders during a social care workforce training project in 2014 and 2015.

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It is not possible to name each one here, but countless intuitive and compassionate professionals have supported us along the way, and we appreciate their kindness and dedication.

We are grateful for the ongoing help we receive from organisations such as the Alzheimer's Society and local community projects, which are recognising and responding to the needs of younger people with dementia.

Finally, we acknowledge the wonderful work of YoungDementia UK in giving a voice to people like us and wish them every success in their continuing efforts to champion our cause.

In memory of Theresa Goode, Ted Clayton-Turner, David Watson, and others we have loved and lost to young onset dementia.

Foreword

Having contributed to this project, it is of no surprise to me that the report has a degree of familiarity. What I had not anticipated was how deeply profound many of the comments would be, and how precisely they articulate my own feelings and situation. I have never read anything that does this quite so accurately before.

Whilst many carers may feel isolated, and believe their challenges to be unique, it is a relief to know that others have similar experiences, offering the potential for dialogue, learning and community.

The more you become enveloped by the intensity of your own circumstance, the harder it is to feel connected to the everyday world. Through the powerful words spoken in this report, I feel strongly that care professionals will be provided with a depth of insight that would be difficult to appreciate unless experienced first-hand. I hope this publication will help them to imagine and understand some of the more complex dynamics, where life's practicalities interweave with powerful emotions, and, in turn, enable them to provide us with more wide-ranging support.

I expect that many contributors feel a moral imperative to share their experiences, no matter how exposing. As we inevitably move towards a more fragmented and socially remote existence, our public persona becomes less of a



preoccupation; we are too busy managing the day to day. What we cannot avoid, however, is the pain, heartbreak and overwhelming responsibility that could never have been envisaged.

We battle to keep a grip on our lives against a cruel, unpredictable and unrelenting enemy.

Paul Sinclair

Summary of key messages

The impact of being diagnosed with dementia at a young age is huge and can be deeply painful. There is greater potential than with later diagnosis for life to be disrupted and confidence lost following the common experience of having to give up work and other roles that provide meaning and significance in life.

People with young onset dementia are determined to continue with 'normal life' as long as possible and require a dementia friendly world of work, leisure, commerce and community if this is going to be possible. Occupational health services could enable the person with dementia and their carer to leave work in a way that is dignified and of their own choosing.

The shock waves of a diagnosis at a young age reverberate. The lives of partners, children, parents and friends are touched, and a new way of being together must be found. The primary carer is at risk of physical and mental stress because of the many competing demands on their time and energy. Keeping relationships strong is a priority, as it is the informal networks on which younger people with dementia rely most heavily for support.

People with young onset dementia struggle to find a diagnosis, and when they do receive one it is more often of a rarer condition. They and their families need specialist advice and support in learning how to understand and cope with the symptoms and live life to the full.

Because young onset dementia has been considered rare, there has been little impetus to provide specialist services, but being in services for older people can have a detrimental effect on a younger person. There is a pressing need for more age appropriate help.

The severe emotional and psychological consequences of a diagnosis of young onset dementia require a range of effective sources of support. This includes specialist one to one counselling and advice, from those who understand young onset dementia, but also ideally a range of settings where people can meet others in their situation and gain mutual support.

Conventional day care and domiciliary services tend not to meet the needs of younger people with dementia. New models of support could be developed that are acceptable which would involve opportunities to be active and outdoors, pursuing interests and engaging in purposeful activities. They would encompass long enough periods of funded help to allow the family carer to continue with paid work if they so wish.

It is not unusual to live with young onset dementia for many years, meaning a large proportion of the carer's life is shaped by their support role. Carers need long-term help to negotiate the stages of dementia, make decisions and maintain their own health and well-being. This may include support in finding full-time and end of life care. Help should not stop when the person dies, as it takes years to work through the grief and find a new way of life.

Pioneering organisations across the UK have developed innovative ways of supporting younger people that can provide ideas and inspiration for new projects to fill gaps in provision. We hope that others will follow their lead.



Introduction

Being diagnosed with dementia when you are still working age is different from being diagnosed when you are in advanced old age. It is a relatively rare experience, and not something we expect to happen to younger people, and yet latest estimates identify over 40,000 people in the UK with young onset dementia (statistic taken from Dementia UK Update, published by the Alzheimer's Society in November 2014). Our guide tells the stories of younger people and their families so that their social care needs can be understood and help offered that is sensitive to the distinctive life issues they face.

With funding from the Department of Health's Workforce Advisory Group, Dementia Pathfinders ran a training project on young onset dementia in late 2014 and early 2015. The project was informed at every stage by active involvement of people with young onset dementia and those in family caring roles who generously told their stories.

We began by listening in detail to their experiences which were then translated into a two-day training course, co-delivered with people with young onset dementia and carers. The listening process generated rich material which forms the basis of this resource. Twenty three people gave detailed reflections; fifteen were primary carers and eight were people with a diagnosis of dementia. These conversations lasted between one and three hours. Briefer contacts were made with another 20 people affected by young onset dementia.

This guide is based on the combined insights and opinions of the people who have contributed to the project from personal experience. They have commented on the structure and content, and have contributed stories and examples that illustrate the messages we want to convey. Our aim in producing the guide is to help those providing social care and support to grasp the reality of life with young onset dementia. We hope this will lead to intuitive and respectful interactions, but also an impetus to find new and better ways of working that take account of the needs of younger people.

There are a variety of ways to talk about dementia when it happens in earlier life – 'working age dementia', 'early onset dementia', 'young onset dementia', for instance. We use the term 'young onset dementia'. When we talk about 'carers' we mean the people who provide care and support because they are in a close relationships with the person with dementia (relatives and friends), rather than those caring in a paid or voluntary capacity.

This resource is written in the first person – 'I', 'we', 'us', 'ours' – as we would like to convey the collective voice of those who contributed life experiences. All of the ideas and perspectives included were expressed by people living with young onset dementia, or those supporting a friend or family member, during the course of the project.

'In some ways I was pleased when my diagnosis of dementia was confirmed. I didn't know and couldn't understand why I was having such problems. The children were very good; I mean they had to be told. I did find this difficult, and made sure my husband was with me when we told them, because I knew we all had to be together to do it. I have good days and bad days. I'm still surviving! But I do find sometimes it's difficult, particularly in the afternoon. Whether it's just because I'm tired, or something more than this, I don't know, but I find the afternoons very difficult. My husband has been superb (and he always will be, I know), but there are times when I really don't know what I'm doing: 'why am I here, what's happening?' But we've got to keep going.

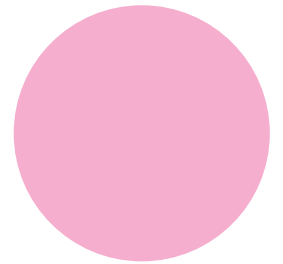
'I certainly still enjoy life and my husband and I do a lot together. I'm still looking after the house; I enjoy doing our wonderful garden and allotment, which takes up a large proportion of our time, but keeps us busy! I still love reading. We enjoy walking together, particularly walks along the beach which is very close to us. When it comes to dementia, you just have to take it a day at a time.'

(Extracts from Rose's chapters in *Welcome to Our World: A Collection of Life Writings* by People Living with Dementia, published in 2014 by Forget-Me-Nots, Canterbury,

ISBN 9780993074202, available at £5.00 from shop.alzheimers.org.uk or waterstones.com, proceeds to Alzheimer's Society)

PART 1

Understanding the changes for the person and those close to them



1.1 How people with young onset dementia feel about their lives

This chapter describes the experience of living with young onset dementia, from the perspective of those who took part in the project with Dementia Pathfinders. All are things that have been faced by us. We have not each been through every experience listed, but they are representative of the group's lives. We have included case studies from other people with young onset dementia that reinforce our message.

In this section we invite the reader to imagine what it is like for us to be living with a diagnosis usually associated with much later life. Many of the feelings and challenges we face mirror those of older people with dementia, but receiving the news you have dementia at an earlier stage of life has a different impact.

A SUDDEN CHANGE OF COURSE

It is never pleasant to notice your brain letting you down, whatever your age, but if it happens in your 70s or 80s you recognise this as a not uncommon hazard of living long. The ages of 30 to 60 see the peak of energy and achievement in life, and dementia is the last thing you expect to encounter. In our middle years, our lives are full; we have many roles and responsibilities at work and home. Other people rely on us, and we have plans for the future, including a retirement to enjoy the fruits of our labours and focus on the things we value in life.

Picture having this momentum and direction suddenly interrupted by a condition that will potentially affect every aspect of your life. Imagine being told you have a disease which everyone around you associates with old age.

Life unravelling before diagnosis

It can take a long time to receive a diagnosis of dementia when you are younger. If you report your concerns to your GP they will often attribute problems to another cause – stress at work, depression, menopause, for instance. Because we more typically have rarer types of dementia, the symptoms may not present initially as dementia. While waiting for a diagnosis, life may start to unravel. The job we have done competently for years becomes more taxing, and we may make mistakes for which colleagues blame us. At home, our relationships come under pressure. Our partners and children cannot understand the changes and may be irritated, something they regret when the true situation becomes clear at diagnosis.

'As far as the GP and I were concerned, my wife was suffering from depression. In my naivety I just thought depression meant you were unhappy all the time. She was pretty low but there seemed to be more to it than that. She used to love taking the neighbour's dog for a walk. One day she didn't come back. It had started to rain and I searched the village with no luck and called friends to see if she was with them. I was about to call the police when an RAC van turned up with a drenched Brenda and dog on board. The RAC Man had found them cowering by the side of a main road looking lost. There are good Samaritans around! She got lost when driving too. Once I was out searching and found her on the hard shoulder of a motorway frightened to drive further. She was very house-proud but things went downhill despite her insisting she'd "spent hours cleaning"! We had a new cooker installed and however hard I tried to teach her how to use it, she just couldn't. I'm afraid I was rather impatient which didn't help. This depression was very strange. We tried all sorts of remedies including going to someone who dangled a crystal over her head. It didn't work. Life was beginning to get very difficult and we were both unhappy all the time.' (Peter)

Working lives ending

All too often our working lives come to an end abruptly, painfully and needlessly early. In exceptional situations, employers find ways to keep us in work by accommodating our needs. More commonly we face redundancy or early retirement. This brings devastating consequences:

- We lose income and may get into debt because we cannot keep up with rent or mortgage payments unless given timely financial and legal advice;
- We are left at home, looking for ways to fill our time, while our peers are out at work;
- We are stripped of a key source of identity and self-worth;
- We lose social connections, no longer having a network of colleagues and contacts from work.

Very few people diagnosed with young onset dementia are glad to leave work. The anguish and regret felt over how work ended can often live on well beyond leaving a job. Being fired because you supposedly weren't doing your job properly is not how anyone would want their career to end. We miss our work and often wish we were still able to employ our skills and energies in productive activities.

Relationships coming under strain

Relationships change too. Some relatives and friends are better than others at adjusting. We may have dependent children – either of school age and living with us, or young adults who are still emotionally and financially reliant. Dementia makes it harder to meet these parenting demands. The easy give and take in relationships with our partners is also disturbed. We have to find new ways of being together and we can easily feel bad over being a source of stress and heartache for them.

An uncertain future

In so many ways, being diagnosed with dementia young disrupts life. Everything is thrown up in the air, nothing is certain. The plans we made for the future seem destined to fail. It takes time and support to come to terms with the new and unwelcome direction our lives are taking, so try not to be surprised if we express anger and resentment. It is natural to feel cheated and to

be frustrated and sad when friends carelessly talk about their lives carrying on as normal – their holidays and adventures, promotions at work, retirement plans. This is a painful reminder of things we have lost.

THINGS THAT CAN BE DIFFICULT

'A key factor for me is frustration: frustration with the impact dementia has on me as a relatively young person; frustration around the lack of appropriate care both now and as the condition progresses; frustration around the lack of understanding, bordering at times on disbelief that I have dementia from people I meet. I live with constant concerns. There are concerns around the fact that physically (thankfully) I am well but mentally and emotionally I am much more affected. Also, there are concerns around how my progressing dementia makes those close to me – wife, grown-up children and grandchildren – view me.' (Keith)

These are some of the negative things about living with dementia as a younger person. We don't experience all these difficulties all of the time, but we are at risk of them:

Frustration – having limits placed on what you can do at such an early age is frustrating. You have the physical capacity still to do most things, but your brain is not letting you. You want to socialise with friends and family, but keeping up with conversations and finding the words is more difficult. You want to channel your energy through being outdoors, but you are losing your sense of direction and at risk of getting lost. Everyday chores like cooking for the family present a challenge. There is a threat you will lose your driving licence and the freedom this represents. Countless moments each day have the potential to leave us feeling flustered, even

angry, that we are in this situation of struggling while everyone else around us seems to be coping fine with life.

Fear – we may have given little thought to the future, caught up in the demands of day to day life, but dementia has brought us face to face with how our lives are likely to end, and it is not something on which we want to dwell. The thought of what we will lose along the way is truly horrible and brings troubling questions. Will I know my grandchildren? Will I be able to stay living at home? Will my partner still love me? Some fears are more immediate, like the fear of getting lost when out, or feeling frightened of the dark because of changes in visual perception.

Insecurity and loss of confidence – on the outside nothing has changed, but inside our confidence has ebbed away. Having a brain that can no longer be relied upon causes insecurity and, though it can be hard on the people close to us, we feel more relaxed when they are with us; feeling safe and assured is increasingly linked to them being present. While we hope that they feel better when they are with us too, it is a change in the dynamic of our relationships. The old independence and self-reliance we took for granted is eroded by dementia.

'I used to help Brenda to bed each night and then go back downstairs for my daily respite, which usually included a glass of wine I'm afraid. Then one night she just wouldn't get into bed. She seemed frightened about something. After a lot of gentle cajoling (I'd become a lot more patient and caring since the diagnosis) I got her to tell me what was wrong. She said that she'd seen someone on top of the wardrobe. Then they were underneath it and then inside. After a lot of explaining that there was nobody there, I managed to persuade her to get into bed.'

This was the start of a pattern and each night someone was in my office, in another wardrobe or outside the bedroom door. Every night it took longer to calm her and at times she was almost hysterical. With everything else that was going on this sent my stress levels through the roof. In the end a very mild antipsychotic solved the problem (they do have their genuine uses!)'. (Peter)

Exhaustion – having to concentrate hard, even on the simplest of things, makes life tiring. There are lots of straightforward tasks we used to do with scarcely a thought to which we now need to apply ourselves carefully if we are to complete them successfully. We may look fit and strong at first glance, but our stamina for mental exertion is less. We need times of rest and quietness to recuperate after periods of mental effort.

Feeling you have let people down – we know it is not a rational feeling (after all, we did not choose to have this condition), but we feel guilty sometimes that we have brought this stress into our families and friendships. It is not good to feel that you are a burden to those you love, or that your condition is stopping them doing what they want in life. We sometimes voice these feelings in strong terms; *'why don't you just shoot me?'* At other times we simply withdraw and become depressed and tearful. It is difficult to see your partner and children labouring over tasks you used to do, watching them become tired and stressed under the extra work and pressure.

Despair – so it is not surprising that we live with the ever-present spectre of depression, reaching rock bottom and wondering if there is anything worth living for. There are so many losses to accommodate that we live with grief – loss of work, loss of income, loss of roles in family and friendship, loss of purpose, right down to loss of a future.

Loneliness – there is a common experience of loneliness in dementia, regardless of age, but it can be worse when you are diagnosed young:

- You may have to leave work which was a major source of friendship and social contact;
- But your friends and neighbours of the same age are still in paid employment so not available during their working hours;
- Some friendships evaporate because they cannot withstand the changes that dementia brings, and it is hard not to feel hurt and resentful;
- Social activities organised for people like us, with dementia, are geared towards older people and reinforce your feeling of isolation by asking you to socialise with people of your parents' generation;
- Because it is relatively rare to have young onset dementia, you can feel you are the only one. It is difficult to find others in your situation;
- It is hard to fit in anywhere. Out and about the general public cannot accept that you have dementia and even express disbelief. You are out of place wherever you go.
- Finally, and sadly, dementia still carries stigma, fear and misunderstanding, rather than acceptance, making us sometimes wary about telling people we have this problem.

Feeling belittled – because of the fear and misunderstanding about dementia, we are not always treated well by the general public. We want to tell them that having dementia does not mean we cannot think or feel. Being spoken

to as if you are stupid has an impact on our self esteem. This sense of being diminished is made worse when we are 'dropped' by friends and former colleagues.

Boredom – we have energy and skills we want to use, but a major source of creativity and purpose in adult life - paid employment - has often been taken away from us. If nothing fills its place, we are left with endless idle hours. There are very few organisations offering purposeful activity for younger people with dementia. We are looking for social occasions, opportunities to pursue hobbies and interests, and voluntary work. Having positive dates in the diary to look forward to helps lessen the sense of futility and boredom.

Distressing psychological symptoms – dementia is often accompanied by horrid psychological symptoms which can be hard to tolerate. Moments of acute anxiety and stress can take hold when we are in situations of pressure which trigger panic or disorientation. At times we may find paranoid thoughts creeping into our minds, when we may be convinced that our partner is having an affair, or that people are stealing things from us. Night terrors may visit, robbing us of a peaceful night's sleep. These brain changes are especially frightening, as they are unpredictable and we have little control over the symptoms.

FINDING A NEW WAY TO LIVE

It takes longer for younger people to receive a diagnosis because doctors tend not to consider dementia as a possible reason for our problems because we are young. All sorts of possible causes for our cognitive problems may have been considered, such as depression and hormonal changes. It can be a relief finally to know what the cause is, to have an explanation, however, coming to terms with having a

condition usually associated with old age takes time. Some never reach a position of acceptance and are reluctant to admit that they have dementia, but it is testament to the human spirit that many people with young onset dementia come across as cheerful and resilient, and are able to point to good things in their lives.

Wanting to carry on living as 'normal'

Several who participated in this project received alarmist messages during diagnosis, suggesting they should cancel planned holidays, give up driving or stop working straightaway. So we want to emphasise that life need not change dramatically. Dementia progresses gradually and the symptoms are mild initially if you are diagnosed in a timely fashion. You do not need to put plans on hold or limit your life unduly. Learning to live with dementia includes continuing doing things you enjoy and keeping life as 'normal' as possible. You might need to adapt activities slightly, but life is not over!

Making the most of life

Receiving a diagnosis of a life-limiting condition tends to concentrate the mind. It helps you recognise what is important, clarifying life goals and helping you identify things you want to do. Dementia forces you to make the most of every day, to live in the moment and cherish times of fun, intimacy and discovery. You find a new strength within and a depth to some relationships which become closer through the hard times. New friendships can be made, for instance with others with the same condition.

'After his diagnosis, Jerry and I felt strongly that we had to make the most of every day, doing normal things that others our age would do. We spent a lot of time visiting National Trust properties and museums as we have both always enjoyed history and architecture. As dementia

progressed we went to some places so often we did not even need to present our membership cards as we were so well known. They were a great source of gentle outing suitable to the needs of the person while enabling us both to get something out of the trip at an appropriate level. There was always tea and cake too!’ (Sue)

KEYS TO LIVING WELL

If we are to live well with dementia we need those around us to embrace the approaches that will help us.

Being in control and maintaining independence

The changes dementia brings make us more reliant on other people, but we still want to feel we have control over our lives. We want to make decisions and to have choices, even if this involves taking some risks. This is **our** story – we each tell our story of dementia in our own way. It is important we keep hold of and are respected in telling our version of what is happening. We may not always be factually correct, but we need an explanation that makes sense to us, so please try not to contradict what we say about our dementia. Our home is our domain and we want a say over how it is organised, even if this means others find it untidy or less pleasing to the eye. How we spend our time also needs to be shaped by our preferences and we want to dictate the terms of any support plan. Forgive us if we are reluctant at times to accept help from outside our close circle – this is less easy for us to control, so you can see why we might resist.

We want to sense we are making a contribution still. Being side-lined is hard as it is a human instinct to want to feel needed. There is a natural channel for our love and care in family life and friendships, and it matters to us to feel that we are giving that nurture and support to the people we

love. Being able to continue in paid or voluntary work, however, is also a useful channelling of our skills and energy. Several participants in this project contribute actively to the well-being of children in their social group, or look after pets on behalf of friends. A number had excellent help from employers that enabled them to continue working. Some are active in community groups where their practical contributions are valued.

Self help and peer support

The most effective ways of coping and living life to the full come from within us individually or as a peer group helping each other.

We would like to know at every point in our dementia what we can do to help ourselves. Whether it is through cognitive strategies, assistive technology, or general health tactics, we want to keep our minds and bodies well. Caring for ourselves is a way of keeping our self-respect and staying in charge. Guidance on what might help, and how to achieve it, is important.

It helps also to know that we are not alone, that others face the same challenge of diagnosis of dementia while still young. Some of us (though not all, by any means) have a firm desire to meet with other younger people with dementia. We can feel an outsider in groups of older people with dementia, but there is a sense of camaraderie and the possibility of sharing ideas for coping if we are given opportunities to be with other younger people. A proviso, however, is that opportunities for this ‘peer support’ work best when carefully planned. We have had painful experiences when meeting people at a more advanced stage of dementia, or where communication problems have arisen, and this can do more harm than good. Sometimes hearing about the difficulties others face (including through online forums) can make us feel more depressed about our own lives.

BEING ABLE TO USE OUR ENERGIES AND ABILITIES

'Until April 1st 2011, I was head teacher of a very large primary school, was studying for an MA, and was advising other Canterbury schools on behalf of Kent County Council. All that stopped with my diagnosis of Alzheimer's disease at the age of fifty-five. After devoting five months to my dementia assessment, and then five more months to come to terms with that, I decided that I needed to continue to try and play a useful role in society and utilise some of the skills which, although waning a little, were still available to me, in order to raise awareness about what living well with dementia is really like.

'Quickly I was offered a voluntary role of 'Dementia Envoy' with the Kent and Medway NHS Social Partnership Trust, and then became a very busy person. I felt a greater impact could be had if others shared carrying the baton with me. Consequently in November 2012, six people with dementia and two clinical psychologists met to form what professionals called a "Dementia Service User Network", but which we insisted should be called the

"Forget-Me-Nots". The function is partly social comradeship and partly to be a useful resource to the NHS Trust in the area. Four regular elements within our commitment are: being on interview panels for posts connected to dementia care; we analyse and comment upon dementia related literature being generated by the NHS; we have participated in a number of worthwhile projects with DEEP (Dementia Engagement and Empowerment Project) and are active supporters of this very important venture; we speak at conferences and at post-diagnosis groups where often people in the audience have not long been diagnosed and are coming to terms with this and welcome hearing our experience and positive advice.'

(Extracts from Keith's chapters in *Welcome to Our World: A Collection of Life Writings* by People Living with Dementia, published in 2014 by Forget-Me-Nots, Canterbury

ISBN 9780993074202, available at £5.00 from shop.alzheimers.org.uk or waterstones.com, proceeds to Alzheimer's Society)

A dementia friendly world

Many of the challenges of living well with dementia are lessened when the world around us accommodates our disability. As younger adults, we expect to spend a lot of time out of our homes, so the welcome we receive in our local shops and leisure facilities is crucial.

We can recount wonderful stories about the 'kindness of strangers', when members of the public have helped out, but we know that those

with dementia are not always treated well in public places.

The physical environment can be off-putting, with poor signage and lighting and noisy spaces that can be bewildering. Awareness of the needs of people with cognitive problems in those in public facing roles is growing, and we support this. We also need our close friends and relatives to understand our limitations and know how best to support us to stay involved.

KEY POINTS:

- Being diagnosed at a young age with dementia changes your life utterly;
- We experience a broad range of painful feelings, including loss, frustration, depression and anxiety, poor self esteem, guilt and loneliness;
- We can find ways to continue living our lives with the right support.

'After my diagnosis of fronto-temporal dementia, I thought we just had to get on with our lives and that's it. How wrong was I?! After attending some coffee morning groups, which were not for me, I was invited to join the Forget-Me-Nots group in Canterbury. This has opened a whole new life for me. We are a really great mix, and we like to get everybody's view. This is very important as everybody's experience of dementia is different. I have sat on interview panels for different grades to work with dementia. I have spoken at memory clinics about how I cope with living with dementia, and about what support is available.

'Who would have thought it?! Here is me with a diagnosis of dementia and I'm involved in all these things. Now, I know this might sound strange, but there are benefits to

having dementia: all the things we are doing for the future for people with dementia, all the great people I have met in our group and at meetings and interviews; letting people know about dementia, and that it's not a death sentence, and there are lots of things out there for you. Certain things become more difficult. Simple things are not so easy anymore, but you have got to do your best to get on with your life as best you can'.

(Extracts from Chris R's chapters in Welcome to Our World: A Collection of Life Writings by People Living with Dementia, published in 2014 by Forget-Me-Nots, Canterbury

ISBN 9780993074202, available at £5.00 from shop.alzheimers.org.uk or waterstones.com, proceeds to Alzheimer's Society)

1.2 The impact of young onset dementia on those who are close to the person

The experiences described here have all been shared by those of us in caring roles taking part in the Dementia Pathfinders project on young onset dementia. We share some things in common, but we each have our own perspective. Through telling our stories we hope to raise awareness of what happens in relationships when a person is diagnosed with dementia at a young age.

A CHANGE OF LIFE

A dementia diagnosis does not just affect one individual but all the people close to them. We remember the moment we realised life would change forever. We may have harboured concerns for several years, and the diagnosis may confirm what we already knew, but it still comes as a shock. It is a lot to take in, and we do not easily absorb all that we are told straightaway. In the early days the adjustment is mainly emotional and psychological, as the symptoms are still mild. At this stage we do not want to be defined as 'carer', but as husband, partner, daughter, for example. We may be conscious of some major decisions looming in the not too distant future, but in the here and now our priority is to enable the person we care about to continue with their life as fully as possible.

There are subtle changes in the relationship from the start, a gradual rebalancing, but the person is usually their familiar self, as able as before to give us support and affection. The mutual aspects remain. In forms of dementia which

affect the frontal lobe of the brain early changes to personality tend to be more obvious in the milder stages. Of course doubts assail us, such as whether we will be able to cope, but the desire to provide support to the person is stronger.

The sense of loss we feel in these early days is often over the future, recognising that hopes and plans we made with the person will need to change. We have many questions about the diagnosis and what to expect and are eager for knowledge and for guidance on how we can help the person.

THINGS THAT CAN BE DIFFICULT

We have many positive and hopeful stories to tell from our experience of supporting a person with young onset dementia, but here we would like to share some of the things we find hard.

'The emotional impact of caring is huge for us all as a three generational household. We are losing Mum. Her dementia means things

are slipping faster than ever. We have to think through whether involving Mum in activities away from the home, and out of her routine, will have a positive effect. The children understand that creating memories is important, that their grandma might not remember but they will. The mix of emotions is difficult to balance. Sometimes I feel so grateful to be able to care for someone who cared for me. Sometimes I feel exhausted, like doing my best is never good enough. I often feel frustrated that services don't fit us. We are allocated four hours of support for Mum a week, we care for her 24/7. I find myself in conflict situations with health and social care professionals who don't understand what it means to care for someone with a dementia. Sometimes I just want my Mum back, as she was, for one day, just to check in that I am doing my best for her.' (Suzy)

Grieving

Losing someone to dementia is often described 'a long bereavement', which starts when the condition is diagnosed and continues until beyond the person's death. If anything the grief is heightened when a diagnosis comes young, because there is a greater sense of being 'robbed' of a portion of your life. A phase of life to which you have been looking forward – the freedom of early retirement – seems to have disappeared. Your friends' lives seem to be carrying on and, in tactless moments, they tell you about exciting things they are doing, but your own life is on hold.

We grieve most for the relationship as it was, seeing how dementia is changing it. We may miss the intimacy we once knew if our partner is the one with dementia, and we are pained by changes in personality that begin to emerge. We mourn for the liberty and enjoyment of our previous care-free lives. When the needs

of the person prompt us to give up our paid employment, we miss this too. We miss 'normal' family life and friendships.

Feeling uncertain

The changes dementia brings are complex and for most of us this is entirely new territory. We want to understand what is happening for the person we care about and how best to help them. This is not a one off need for information, but ongoing, because dementia is progressive. Something that works well today might not be effective next month. In an ideal world there would be someone alongside us in those difficult moments when we do not know what to do for the best, someone who could suggest what to say or do to ease a stressful situation. We especially value help in making big decisions at times of transition when it can be hard to know which way to turn.

Feeling the pain of the person with dementia

When you are in a close relationship with someone, their pain is your pain. We have times of deep distress caused by seeing the person struggle to cope with the changes dementia has brought. It is heart-breaking to hear them talk about their lost sense of who they are. Watching the anxiety and bewilderment communicated in their face can be agony. Their sadness is mirrored in us, but we try hard to maintain their morale, seeking to reassure and boost confidence against impossible obstacles, showing a cheerful face but crying inside.

Feeling alone

You are on your own if someone close to you has young onset dementia because it is relatively rare. Your experience is not shared by many in your peer group or locality. This sense of being on your own is reinforced when friends and relatives seemingly abandon you. The sense of isolation

partly stems from the way dementia changes the relationship to a person who has been a long-term source of affection and support. They may be less able to recognise and respond to your needs, and you are less able to confide in them your true feelings. You miss this intimacy, and possibly also the sexual dimension of the relationship as this becomes more difficult. Sometimes changes dementia brings to personality cause shock and sorrow too; the person may say things that are unkind, or even show physical violence, in ways that are completely out of character, which can be very frightening when you consider that they are still young and strong. You feel you are losing the person you knew, and it underlines the sense of loneliness.

If we lived in a dementia friendly world, it would be easier to stay connected socially, but we cannot

be sure others will understand if the person with dementia says or does unusual things. We risk embarrassment in public places, so there is a temptation to stay safely at home and avoid environments that are less easy to control.

Dwindling resources

If you are supporting a younger person with dementia, this role may span many years. It is important you conserve your energy and look after yourself, but this is not always easy when your focus is on the person with the diagnosis.

Lots of aspects of supporting a person with young onset dementia can be exhausting. Being asked the same question time and again, and having to answer patiently, or provide constant reassurance, is tiring; we inevitably lose patience occasionally and then feel guilty. Younger people

'Elaine and I have been married for 35 years now. Elaine was adventurous and sporty, and we spent our holidays walking and camping. We couldn't have children, but I think that made us even more reliant on each other. In 2006 I started noticing subtle changes in Elaine: alterations in her behaviour patterns and character, some so small they are hard to describe. She would be a bit repetitive. She said she kept being told off for making mistakes at work, but didn't know why. In 2009 we eventually got a diagnosis of Pick's disease. There are few services available for younger, mobile people. Despite this terrifying diagnosis, we received no counselling.

'I became a full-time carer. I have to watch out for her 24 hours a day. For me it's very lonely. Your life shrinks. Our families live quite far away

and Elaine can't hold a conversation anymore. The worst time is in the evening, especially in winter. We rarely socialise now because she gets agitated in new places or with other people in the house. There is a desperate need for more support for people with early onset dementia, and counselling and training for their carers. My worst fear is that something will happen to me – because then who will look after Elaine? If I am not with her, she can get agitated and distressed. We are still as close as we can be in the circumstances. Of course I still love her. I know that her essence is there, even though the Elaine that was has gone.'

(Taken from The Guardian Newspaper which featured Keith Brown's article on caring for his wife Elaine, diagnosed at 56 with fronto-temporal dementia, on 21 November 2011)

with dementia, being physically strong, are often 'on the go' and it can be hard to keep up.

Then there is the exhaustion of having to think and remember for two people – to remember appointments, to plan ahead, to assess situations, to make decisions, on their behalf as well as for yourself. We have to take on a greater share of parenting, if we have children together, being mum and dad as well as caring for the person with dementia. Because it is difficult to initiate activity in dementia, and boredom is an ever present threat, we have to think about and arrange things that will fill the person's days pleasantly and purposefully. This also requires mental energy.

Add to these additional roles the potential for broken sleep when dementia affects normal daily rhythms, and it is not difficult to understand why many carers of younger people hit a wall of complete exhaustion from time to time. The objective answer to this periodic burnout is for us to accept respite care, but this is not easy. We know the person we care for does not want other people involved and we can feel it is a betrayal to take time for ourselves. It is a matter of pride to feel that you are coping and to tell the world at large that you are 'fine'. We often under-estimate how taxing life is and carry on hurtling towards a crisis when the demands of caring push us beyond breaking point.

In practical terms, carers in this project found their financial resources dwindling too, because of lost income from employment, and this only adds to the stresses. Some only stumbled upon good financial advice to enable them to plan ahead and maximise income.

Worry

Worry is a constant companion. Sources of worry are plentiful:

- How will we pay the bills if one, or both, of us has to give up work? We still have significant financial commitments, such as a mortgage or funding children through college;
- Should I carry on working? Is the person with dementia safe and happy while I am at work?
- If the person is our partner and we have children, what will be the effect on them in the long-term?
- What will the future hold and how will we manage? We may want the person with dementia to remain at home, but feel anxious this might not be possible.
- Am I doing the right thing? There are constant ethical dilemmas brought by having to make decisions for another person and assess levels of risk in some of their choices.
- What will my life be like if the person I am caring for has to go into a care home?
- What will my life be like after the person has died?

Feeling trapped

Some of us sensed at the moment of diagnosis that our lives were forever changed. Choices were removed and we were set on a course outside our control. At a stage when greater freedom was opening up perhaps, we suddenly found ourselves constrained. All our decisions are now limited by the dementia. This includes the big decisions about whether to work or where to live, and how to spend our income, but it also shapes the tiny details of every day.

It is strange recognising the person we knew as a self-sufficient, resourceful adult needs us much

more now. They want to be with us more than before because our presence gives reassurance. Much as we care and want to do the best for them, it can feel stifling at times. The home is a refuge but can also feel like a prison if you are stuck indoors, reluctant to leave the person with dementia on their own lest they become anxious. Even inside the home, personal space may be limited; if you are living with a damaged brain you may find it difficult to accept the person you depend upon is nearby if you cannot see them. There is also the possibility they may come to harm if left alone, leaving you uneasy unless you are watching them. Any relationship is placed under strain if you live on top of one another.

Conflicting obligations

The stage of life we have reached when dementia strikes young means that multiple legitimate claims on our time and energy compete for finite resources. You don't want your caring role to damage other relationships, particularly those with children and grandchildren who depend on you. There can also be a stressful conflict of priorities between paid work and caring roles. No matter how far you stretch yourself, you still feel you are falling short.

Losing a sense of who I am

Little wonder then that our sense of who we are, and our own needs, starts to vanish. When time is scarce, the things that are pushed down our list of priorities tend to be the things that help us replenish our resources and express ourselves. We may have relinquished paid work and voluntary roles that embodied our sense of who we were, and we may have lost contact with friends and colleagues who reinforced our identity. We start to forget who we are and what we want from life, in the struggle to maintain the well-being of the person with dementia against the ravages of this relentless disease.

KEYS TO COPING AND STAYING WELL

Please tell us we are doing a good job and remind us from time to time to look after ourselves. We may accept logically that we need to preserve our own health and strength, but it is easy to sacrifice our needs in the quest to make life better for the person we care about and just get through each day's demands.

Carving out time for self

'I am still working as an adult education tutor and decided it was important to keep it up because it was a stimulating outlet for me. I had to be very resourceful in getting care, as it was impossible to use normal agencies as they would not guarantee times and I had to be in front of a group of students at specific times. We used relatives, friends, and people we got to know through dementia, even approaching the local day centre to see if members of staff would cover an evening while I was teaching. The money I earned went on care, but we both benefitted by being apart for a couple of hours. Now Jerry is in care my earnings make a difference to my life, as without them I would not be able to keep a car or go on holiday. Teaching also allows me to be myself and forget the limbo I continue to live in, being neither a widow nor a wife. This is a particular problem with young onset dementia, as often those affected live for very long periods with the disease. It is now 11 years since Jerry was diagnosed, but probably 15 years since it started. He has now needed fulltime care for four years.' (Sue)

Holding on to who we are and what we need to flourish will be unique for each of us. Someone who helps us work out the right balance will be greatly appreciated. For some people it will mean opportunities to continue with cherished hobbies and interests, space away from the caring role when our minds can focus altogether

on something else. For others, though, being able to continue working is the key to maintaining identity and mental and emotional stamina. We may want and need to be earning, and our colleagues may be a major source of friendship and support in coping with what is happening at home.

Being able to focus on other relationships

It is easy for relationships with some friends and family to dwindle when you are caring for someone with dementia 24 hours a day. Firstly, they can find it difficult, often through embarrassment, to spend time with the person with dementia. Then, as a carer, you probably change too and are not always the person they knew. It's easier for them not to get involved. However, having time and emotional energy for relationships that matter to us and meet our own needs is crucial. For some of us this means our children and grandchildren, for whom we are providing emotional nurture, having to be mum and dad, grandma and grandpa. We sometimes have elderly parents who rely on our support and are a source of encouragement. Then there are friendships that play a pivotal part in our lives. It is of vital importance these relationships are not squeezed unduly by our new caring responsibilities. Any help we are offered needs to take into account the unique networks of relationships we each have.

Help to be the best carer we can

It is daunting to be faced with a new role in mid life which you have not chosen and for which you feel ill-equipped. You want to offer whatever is needed, but how to do this is not always obvious. We seize opportunities to learn about dementia; having a good early understanding of how the brain works and the likely symptoms of dementia and how to react helps us know what to do in puzzling situations. This need for

education is ongoing because dementia does not stay the same and each person's experience of it is unique. Regular opportunities to talk through what is happening and receive guidance and support are invaluable. This is especially true for those of us supporting a person with a rarer form of dementia, such as CJD or frontal temporal dementia, which may present with symptoms that are not typical of the classic form found in Alzheimer's.

Being with others in our situation

It does not appeal to everyone, but many carers of younger people with dementia crave contact with others who share their unusual way of life. It can be comforting to find out that others are going through similar stresses and useful to hear about ways they have found of coping. This can be through attending informal self-help meetings or through being linked with other carers for one to one friendship and support. Several carers who took part in the Dementia Pathfinders project found the links with others who shared their experiences the most effective way of coping with life. Friendships formed through this means proved enduring sources of social and emotional support. For some they continued even after the person with dementia died.

Times of enjoyment

Though the diagnosis of young onset dementia is devastating, there are chinks of light. We realised that life is not over, there are still ways we can have fun and enjoyment together. In fact, the diagnosis helps us prioritise opportunities that are fulfilling for the person with dementia and those close to them. It forces us to seize the moment and avoid delaying plans for pleasurable experiences. This can be as simple as waking up on a sunny morning and deciding to go for a country walk. Or, if income permits, it could be taking that holiday you always had

in mind. Family celebrations are cherished, and seen as occasions for creating new and happy collective memories. There are few ways we feel thankful for dementia, but we acknowledge that it helpfully forces us to live in the moment and make the most of each new day.

Silver Linings

'This is going to sound very strange, but I wouldn't have missed those years I was caring for my wife at home for anything. Of course I wish her dementia had never happened. But it did, and it brought us closer together. I'd led a busy business life with lots of travelling. She'd had her own interests including being a Samaritan. Her dementia forced us to spend much more time together, appreciate each other more, and despite all the difficulties we laughed a lot. For several years our focus was on one another – I was there for her and she was there with me. Then I just couldn't cope anymore and she went to live in a care home. I was lost with no Brenda to look after, no work, most friends had become remote, and all my interests had fallen by the wayside. The lack of day to day dementia in my life left a void that took a very long time to fill.' (Peter)

Some gains would not have happened without the dementia. Though some friends and family seem absent, others show a depth of love and commitment not previously seen. Some of the families who took part in this project feel that the need to support the person with dementia brought them closer and deepened their relationships. Having to support a parent or grandparent with dementia can bring out amazing qualities in children and young people and build character and resources that will be useful in life. Many of us have also experienced and been touched by the 'kindness of strangers' when members of the public have offered sensitive support and friendship at times of challenge.

Another surprising benefit of taking on the caring role is finding within yourself unexpected capabilities. Though we feel stretched at times, we can see how caring has nurtured hidden strengths. It is deeply rewarding to discover ways of supporting the person effectively to manage their condition and we are proud to see them function well despite their disability. By necessity many of us have also discovered a new assertiveness through having to battle for things that make life better for the person we care about.

The brightest ray of sunshine that breaks through the clouds and keeps us going is, of course, the bond we have with the person with dementia. It does come under attack, and is elusive at times, but it is the force that powers our efforts. That is why caring for a person you do not love and towards whom you feel resentment is not an option. Without the feeling of warmth and respect towards the person, it would be impossible to find the strength to cope with the challenges dementia brings. Where mutual affection is still felt, scope for creating moments of shared joy remains. We hold dear those fleeting moments, even in late stage dementia, when the feeling of connection, of being glad to be together, is palpable. This is what makes us hold on to the person – they are still there, we still belong to them and they to us. Any support and care we receive must recognise this as the source of reward and motivation in caring.

CONSIDERING OTHER PEOPLE CLOSE TO THE PERSON WITH DEMENTIA

'As a family we all received a diagnosis. Our lives changed and continue to change everyday. We have learnt to be in the moment with Mum, and my young girls demonstrate this very well in their relationships with her. They accept who she is now and have learnt about caring at an

early age. We have all learnt to be patient, not always easy, and the different pace of all our lives means we really have to slow down, think things through carefully, and walk beside Mum.’ (Suzy)

A role you take on while caring for a person with young onset dementia is becoming the one who mediates their other relationships. Some of us laughingly refer to this as being their social secretary! Maintaining links with friends and relatives is a key source of well-being and we can feel hurt and let down on their behalf by the neglect we notice from some quarters. We are saddened by the strains dementia places on some key relationships.

Children

Young onset dementia often arrives at a stage of life when children are still dependent. We may have children living at home, emotionally and financially reliant on us. Even if they are young adults, they still look to us for support and practical assistance. As a child or young adult, the person diagnosed may be the one to whom you have looked for guidance and you are still developing emotionally and psychologically and discovering who you are. When the person who provides your stability and reassurance is themselves destabilised by dementia, you feel adrift. For some participants in the project the effect on children has been serious, with mental health problems linked to the diagnosis of dementia in a parent who was a major source of support. This gives us additional heartache and stress, as the ‘well’ parent seeing the impact but unable to change the circumstances.

Children and young people express grief and loss differently from adults. There can be unpredictable mood swings and anger, expressed through behaviour that can be difficult. At school there may also be changes,

with the young person becoming socially withdrawn. Another coping mechanism might be to disengage from family life. The strong feelings might not be expressed as classic grief but are clearly a reaction to what is happening.

Inevitably family life changes when one person has dementia. Previous family activities may need to be adapted, holidays may be more difficult for practical and financial reasons, and there is less freedom in making plans and decisions, more limits on choices. Though we try to shield children and grandchildren from caring duties, they are inevitably pulled into some aspects of support, even if this is simply keeping the parent with dementia company while we pop out to the shops. Usually they are happy with this extra responsibility, but we may still feel guilty at times. We may notice that our young adult children are making life choices related to the dementia, perhaps turning down opportunities to travel with work or delaying moving away so that they can remain involved; while we are grateful for their support, we wonder how their lives might have been different.

Our elderly parents and the parents of the person with dementia

With a younger diagnosis of dementia, it is likely our parents and those of the person with dementia are still living, but perhaps at a stage of life when they themselves are frail, or even living with dementia themselves. It is deeply painful to witness an adult child struggling with dementia and inevitably there is a sense in which you feel it should be you and not them. There is a role reversal because of the expectation that adult children will support elderly parents as they become frailer, rather than the other way around.

As the main carer, we are conscious of the heartache of parents, alongside their own

support needs that stem from advancing years. Sometimes a parent is the primary carer, though this was not experienced by participants in our project; our stories included many examples of carers needing to balance their time and energy between the person with dementia and an elderly parent or parent-in-law. Several of these parents were actively contributing to the well-being of the person with dementia and supporting the main carer through emotional care and kindness and in practical ways, such as accompanying the person to activities. Clearly there is a limit to what they can offer if their own health is poor, and there are challenges when parents live at a distance, but these relationships with the older generation are important and require nurture.

Friends

Significant relationships are not necessarily blood ties or legal partnerships. Friendship is the most valued source of connection and support for many people and it is affected by dementia. As we have noted already, some friends cope better than others with the changes. Friends go through a grieving process if they sense they are losing a soul mate and confidante, someone to whom they have turned for affirmation and affection. It can be hard to find a role and understand how best to continue in the relationship. Friends need help and guidance in finding ways to cope and in our experience they have been a key source of practical and emotional assistance. Their help should not be under-estimated.

KEY POINTS:

- As carers our instinct is to look after the person close to us who has dementia, but we don't always know how;
- Our lives are changed beyond recognition and we can easily feel trapped and overwhelmed by painful emotions;
- We need help and encouragement to look after our own health and the well-being of elderly parents and younger people in the family affected by the diagnosis.

PART 2

Meeting the needs
of younger people
and their families



2.1 The current state of play – a woeful lack of support

In this section of our guide we will provide ideas for meeting the needs of younger people with dementia and their families, including several case studies of effective support. It would be misleading, though, to give the impression that help of this kind is readily available. In fact, areas of the country which provide a good service to younger people with dementia are the exception rather than the norm. A motivation in contributing our stories is the hope that it may result in organisations developing new projects for younger people.

Where are the gaps in social care support for younger people with dementia? Options for older people with dementia are not plentiful, and resources are thin on the ground, but most local authorities have several groups offering social opportunities, support at home, day care or residential places. These activities are targeted at people with late onset dementia. Their clients and members are well into retirement and they are designed to appeal to this generation. Our experience has been that younger people with dementia struggle to fit in. Being the only younger person can reinforce the sense of isolation, or, as one of us phrased it, the feeling of being 'dumped'. Simple things, like the topics of conversation and music choices, leave us feeling out of place. Some day services we have used have overcome this mismatch by involving younger people as 'helpers', working with staff to assist frailer members; we can

form friendships with the other helpers and feel purposeful, but an ideal scenario would be having an option aimed at younger people. Many areas of the country lack this provision.

While the disease process may be similar in older people, having dementia as a younger adult is very different. Our social circumstances and biographical stage give us a distinctive outlook on life. Peer support is recognised as valuable in the national debate on dementia, but our 'peers' are other people diagnosed with dementia while working age. They are the ones who share our experience of working lives and relationships disrupted. We crave contact with one another, and our carers with those in a similar caring role, but links are hard to establish.

There is a risk for organisations in setting up a specialist young onset service, in that the pool of potential users is small and recruiting to fill spaces is challenging. There are some shining examples of good practice, however, which encourage us to believe that more can be done. In the chapters that follow we offer a 'how to' guide for social entrepreneurs interested in responding to our distinctive needs. The checklist we provide is not exhaustive but includes the main considerations we would like to be included in any service development for our community.

KEY POINTS:

- Very little age appropriate help exists;
- Younger people with dementia urgently need services that cater for their needs;
- Carers of younger people with dementia need recognition and support.

'I was in a very demanding job and had great career prospects. At 46 I felt that life was only just beginning for me. The year before this traumatic diagnosis, my divorce had come through and I had been awarded the Public Service Medal for outstanding service to science and technology in Australia. Life was on the up for me. But on that fateful afternoon, everything changed, and I felt cut down in my prime. My daughters were only 19, 14 and 9 years old. My parents and sister were in the UK, so I had no family help.

'Looking back, my prior ability with words and numbers helped mask my deterioration for several years. Even now, I am able to appear seemingly quite normal, despite having moderate to severe brain damage. I see this as my "cognitive reserve". Also I think there may be some truth to the existence of a

"motivational reserve". By keeping motivated, I remain active, socially engaged and determined to keep trying new things. When I was diagnosed in 1995 there was no support for the person with dementia. People with dementia were assumed to lack the insight and ability to be helped. We were written off. This made me feel very angry and motivated me to begin my advocacy for improved services and support for people with dementia, as well as their families, around the world.'

(Taken from Christine's Story on the website youngdementiauk.org. Christine has written internationally acclaimed books about her experience of young onset dementia, published by Jessica Kingsley Publishers: 'Dancing with Dementia', published in 2005; 'Who Will I Be When I Die?' published in 2012. She has her own website christinebryden.com.)

2.2 Emotional and social support

The feelings and needs dementia brings for younger adults are experienced by older people too, but this chapter highlights the distinctive emotional and psychological path trodden by people diagnosed with dementia relatively early in life.

'The Memory Service wasn't particularly helpful after Brenda's diagnosis in 2006. However her condition rapidly worsened and they allocated me a mentor from within their team. She was the Speech and Language Therapist. She persuaded me to try a support group she ran but their loved-ones all seemed to be about 30 years older than Brenda (she was diagnosed at age 59). We had virtually no problems in common. She then suggested I try a support group she ran for carers of people with rarer dementias. They all turned out to be around my age and despite the differences, we all seemed to be suffering from the same sort of problems. We met every month under her gentle guidance. We talked together, listened together, laughed together, cried together. We helped one another through desperate times. It seems that men find opening their hearts to others very difficult – I know I did. But after a while all of us, men and women alike, were talking openly about what was happening in our lives. I discovered that just talking with others in my position was such a stress relieving therapy. That Speech and Language Therapist deserves a medal!' (Peter)

Help through the process of diagnosis

Adjusting to dementia intruding in your life is made harder for young people and their families by difficulties finding a diagnosis. We have often been living with early symptoms for several years before doctors put us on track to receive assessment and diagnosis, first discounting other possible causes such as depression and hormonal changes. During this period of uncertainty, relationships are placed under strain. We are blamed for 'mistakes' at work and at home, and the stability of our everyday existence comes under sustained attack. It can be a relief finally to receive the correct diagnosis, but supporting younger people and their families will include acknowledging the stressful process they have endured and helping work through the resulting tensions and sadness, as well as being alongside in making sense of this earth-shattering news. Specialist counselling services are needed which recognise the distinctive feelings and situations faced by younger people. Close family members also need help coming to terms with the diagnosis, including any children and young adults affected. Some participants in the project have been offered psychological therapy for school age children which is greatly appreciated.

Help through diagnosis should also include information about the condition and services available to support. Again, this information needs to be tailored to young diagnosis and to the rarer conditions with which we are more

commonly diagnosed. Signposting at this stage to specialist organisations and NHS provision is vital. Being able to access help with employment, financial and legal issues is a priority for younger people, who otherwise risk losing paid employment and other sources of income and falling on hard times.

The importance of informal networks and the wider family

'Jerry and I had always enjoyed walking and initially he went walking on his own. Fairly soon he began to get lost on paths he had known well. Family members and friends set up support to allow him to go walking, although distances became shorter and walking much slower. For each of us the benefits were huge, allowing healthy exercise and time out of the house observing nature instead of four walls. Spatial awareness was something that went quickly, so this type of help was invaluable as Jerry was unsafe on his own and knew it, so would not go out unless accompanied.' (Sue)

From the early days, right through to the end of life with dementia, friends and family members fulfil a central role in providing emotional back-up and practical help. Paid professionals and support organisations fulfil a useful role if they enable these informal channels to operate effectively by recognising that they offer the lion's share of help. Any external support should reinforce, and never undermine, this network of care which is the source preferred by younger people with dementia.

Supporting the whole family and wider networks includes considering the needs of children and young people affected by the diagnosis. Our stories show that these central characters tend to be invisible when external agencies look at our lives. Yet the impact on a child is colossal when

one parent is diagnosed with dementia and the other parent is absorbed in supporting them and working through their own feelings of loss. Others affected by the diagnosis include elderly parents, siblings and close friends, all of whom may be overlooked in their struggle to come to terms with the changes dementia brings; these individuals also value a listening ear.

Offering a range of options for emotional and social support

The people with young onset dementia and carers who contributed to this guide varied in how they wanted emotional support. Some were keen to meet those in their position, whereas others preferred not to. Some liked group contexts, others were better in one to one interactions. **The message from this is that one size does not fit all.** Offering a range of options will give each individual the best chance of finding support that suits them.

Several participants in the project had benefitted from talking therapies such as cognitive behavioural therapy and couples counselling. This was most effective where the professional offering the help was someone with experience of working in the field of dementia care. Support groups have been invaluable, both for younger people with dementia in the project and the carers who took part. Again, these gave best help where the group was formed of those living with young onset dementia. Being with carers and people with dementia who were older added less to the sense of mutual understanding.

Several of us were involved in forming our own self-help groups of like-minded people. These groups are 'under the radar' and not linked in with formal services, but provide essential friendship, information and encouragement. They meet in people's homes, or local pubs

and cafes, much as any other friendship group functions. The groups also go out together on trips to the theatre, for instance. We have found this approach can also work well where people with dementia and their supporter are matched carefully with another couple for mentoring or peer support; there is great strength to be drawn from feeling you are ‘in it together’.

Where local charities have set up more formal café-style events for younger people with dementia, these have also been welcome sources of help. They can provide a forum for sharing ideas and information about local services, as well as offering friendship. Often local professionals have a regular presence at meetings and can help with signposting and advice on an ad hoc basis. Knowing where to turn in moments of extreme stress is reassuring. Having details to hand of helplines which give immediate listening and advice is a comfort in anticipating moments of intense pressure.

Social and emotional needs don't have to be met in dementia-specific settings. Many younger people wish to continue to meet people through the usual local associations and leisure facilities. If staff and members of these groups can adapt to accommodate new needs, there is a great benefit in continuing with these ‘normal’ social outlets.

Recognising the distinctive emotional needs of the person with dementia and carer

Though the shock and upheaval of diagnosis is shared by those with young onset dementia and the people close to them, it has a different impact. Being the one experiencing the changes in your own life is not the same as seeing them in a friend or relative and feeling responsible for their well-being. In responding to social and emotional needs, it is sensible to recognise the twin narratives that are being lived by the

carer and the person with dementia. Carers need safe spaces to talk about the frustration, loneliness and guilt they encounter. The person with dementia also needs contexts in which they can express anger and despair without worrying about the negative impact this might have on the person who is supporting them. In our project, couples tended to shield each other from their painful emotions or avoid difficult topics for fear of upsetting one another. Good support allows these individual needs to be acknowledged and met, while keeping the dynamics in relationships positive and resilient.

Whatever the time or place, people can also receive support online at Talking Point, a peer support community run by Alzheimer's Society. A woman shared her story:

“My mum has dementia – I’m new to this and I’m in my 20s. I finally plucked up the courage to google ‘young people who have a parent with dementia’ and I found this site. Everything is so hard – yeah I have loads of people to support me but they don’t really understand what it’s like to have a parent with dementia. She’s just in her 50s and they live hours away from me. My dad is a hero and he’s doing so well but I feel it’s really hard for him. Does anyone else know what this is like – feeling sorry for their parents like this? It’d be great to chat to someone.” L, daughter

L was offered support by several people who wrote replies and one person offered to meet up if she wanted to chat further.

KEY POINTS

- Help is needed during and following diagnosis in coming to terms with dementia;
- Information about dementia and sources of help is especially vital for those who are younger and risk losing work and income in avoidable circumstances;
- Informal sources are the first place people with young onset dementia turn for help;
- Variety is needed in the emotional and social support offered – one size does not fit all.



2.3 Support to continue with ‘normal life’ in the early stages of dementia

Life does not need to change drastically in the early years of living with a dementia diagnosis. We are keen to stress this in giving advice to those who are newly diagnosed and we value help in making the necessary adjustments that allow us to continue doing the things that are meaningful for each of us as individuals.

‘Ted decided to slip into full retirement because of his memory problems but before he had his diagnosis. This meant that he missed out on having his pension made up to 65 as would have happened if he had left through sickness. It also meant that he gave himself no opportunity to discuss remaining at work doing less hours and/or a simpler role. Also nobody discussed driving with us or reminded us that we should inform the DVLA and his insurance of his diagnosis. This meant that, had he had an accident, he would have been driving illegally and without insurance. Fortunately Ted decided to stop driving before any accidents happened. I think employment issues are only beginning to be considered. I have seen that there is now an Alzheimer’s Society booklet with guidelines for employers; the need will grow as the retirement age rises. Ted and I derived much benefit through becoming involved in research. It was stimulating and widened our group of friends, giving opportunities to attend events. We were participants in a research project and were keen to know of anything which might slow down or stop the progress of the disease. Since Ted’s death my research activities have widened and are a major source of stimulation, activity and friendship.

You can register your interest in research at joindementiaresearch.nihr.ac.uk.’ (Angela)

Staying well and finding ways to cope

In the years following diagnosis we can take care of ourselves. It matters to us that we are able to maintain maximum physical and cognitive health so that we can stay independent and live life to the full. Support might include:

- Being offered ideas and opportunities for cognitive stimulation, both individually and in social groups;
- Encouragement and financial help in keeping physically fit, such as negotiated rates for gym membership or to attend dance, yoga or fitness classes, which can help with mental health too;
- Equipment and strategies to aid memory and keep us socially connected, such as touch-screen and mobile phone technologies that are simple to use and may allow family members to keep in touch with us or track our whereabouts. We are younger, so tend to be more familiar with these devices than the older generation;
- Ideas for adapting day to day activities like shopping so that we can still manage them;
- Working out familiar routines in well-known environments that mean we have structure and the ability to go out on our own;

- Support to stay in control of our lives, including putting in place future plans and starting to assemble life story resources which will be important sources of information about how best to meet our needs;
- Person-centred advice, e.g. connected to relationships and well-being.

It would be very beneficial to have a trusted advisor who knows us, understands the importance of involving our relatives and friends, and has a good grasp of the distinctive needs of those with young onset dementia. Each person with dementia - and each family member supporting them - has a unique perspective and their own ways of coping. Our advisor would help us identify and reinforce these sources of strength and resilience. They would help us see that the process of adapting to dementia is ongoing, and would sensitively allow us to

identify our limitations while offering positive, practical tips for managing them. This would be cost effective as it would reduce the need to access more intensive interventions.

Help to continue with activities the person enjoys

Life is for living, and receiving a diagnosis of dementia at a young age makes you realise this with fresh force. The early stages of dementia are times for fulfilling dreams and taking opportunities for enjoyment while we are still able. There is a desire to 'seize the moment' and live life to the full.

Those of us who contributed to the Dementia Pathfinders project have continued with many hobbies and interests, and discovered new ones. These include: yoga; zumba; rambling; cycling; Morris dancing; visiting museums and art galleries; attending musical events; creative

'The last five years have certainly caused me to view my life in a very different way and learn to live for, and in, the moment. In 2012 I was diagnosed with fronto-temporal dementia. As a result of the diagnosis and there being no cure, I was forced to retire from work as a driving examiner. Although it is never good to get a diagnosis of dementia, it was a great relief to finally establish the cause of the challenges that I was having in everyday functioning. I was now able to explain to family and friends the reasons why my demeanour and behaviour was different from the person they all knew well. I joined the Forget-Me-Nots group. I find this group very stimulating and the feeling of friendship and community goes a long way to reassure all our group members that they

are not alone in the strange, and sometimes confusing, world of dementia. As a result of my diagnosis, I decided to live life to the full and went back to playing my Tenor Horn. Most weekends I can be found on a bandstand somewhere in Kent, or further afield. I have adopted the daily mantra "I may have dementia, but dementia doesn't have me!"

(Extracts from Chris N's chapters in Welcome to Our World: A Collection of Life Writings by People Living with Dementia, published in 2014 by Forget-Me-Nots, Canterbury

ISBN 9780993074202, available at £5.00 from shop.alzheimers.org.uk or waterstones.com, proceeds to Alzheimer's Society)

writing; singing; painting; gardening; looking after animals. These activities absorb our physical and mental energy and provide rich sources of enjoyment and stimulation, friendship and creativity.

The interests of younger people differ from those of people well into their retirement. We tend to be more physically active and prefer to be out of the house during the day-time. Any contribution to covering costs and ensuring a dementia friendly approach in local amenities can make a real difference to our quality of life. Some are comfortable explaining about their dementia to members of the public and have been pleasantly surprised by the warmth and kindness shown. Family members might have doubts about this approach, aware of our vulnerability, so careful thought and delicate discussions in families may help in exploring alternative strategies and working through anxieties.

Being in mainstream groups for hobbies and interests helps us feel we are still included in our communities. Those leading groups can adapt activities and give extra support if they understand our cognitive difficulties. Being able to travel independently to activities is part of the enjoyment and freedom we value. This is another matter for dementia friendly communities, ensuring that signage is clear, public transport accessible, and support is available in continuing to drive (if appropriate).

The other 'normal' activity which brings us pleasure is having holidays with friends and family. There are challenges in taking trips, like meeting costs when income is reduced, and negotiating journeys especially when using busy airports. Members of the project group who have taken holidays after the dementia diagnosis

speak enthusiastically of the benefits. Holidays continue to be a high point in family life. For relatives who provide care and support, these times are not always a 'break' or a rest, as the caring responsibilities continue, but holidays bring new and happy family memories to cherish. They are especially significant for those of us with children – a rare space to spend time as a family, appreciating each other's company.

'Because of his age, my husband David did not really fit into the standard day care setting and so we were given a "sitter". Right from the start I made it clear that I did not want him sitting whatsoever and eventually, after a few changes, we came across a wonderful lady who was happy to engage in activities with David. This entailed walking from our home across the local country park to our local bowling alley, where they had a couple of games of bowling, and then went on to a nearby café where they had lunch. Then they had a nice stroll home along the sea front.

'This continued for quite a few years and was amended as his condition deteriorated. Small changes were made, such as turning off the line on the bowling lane when David could no longer keep his feet behind it (this stops the scoring). Other customers at the café would save his regular table for him, and eventually staff would cut up his food before delivering it to the table. He soon had quite a few new friends who would always stop to talk when he was out with me. They also went to the pub once a week for a few games of dominoes, and once again were well received by the regulars, again saving him his usual table and having a little chat. In fact, on one such afternoon the wake of a regular was being held in the pub. The family were insistent that David had his usual table and even brought over a plate of sandwiches. Such kindness shown by complete strangers!' (Gillian)

Help with employment and maximising income

Diagnosed with dementia young, you are not at a stage of life when you expect to be retired from work. Your job not only provides structure, routine and satisfaction, but is essential to maintaining your standard of living. Similarly, if a close family member is diagnosed with dementia at a young age, you will not think automatically of quitting your job, but you may need understanding and support from your employer.

The key goal is that decisions made about paid employment are not forced on a person with young onset dementia, or a carer, but are negotiated and made on the basis of what suits them best. There may be a role for health professionals like OTs to work alongside employers in accommodating the needs dementia brings. A typical example from our group has been the carer enabled to work from home several days each week, or elements of the job role of the person with dementia being adjusted to match their capabilities. Sadly many who took part in the project found work coming to an abrupt and traumatic end which left them reeling.

The preferences of primary carers are individual. Some want to continue working full-time to provide an income for their family, now and in the future; they may also see work as a 'break' from caring, and a source of friendship and support where colleagues are understanding. Others choose to give up work because they want to spend as much time as possible with the person with dementia. Each carer needs support in recognising and realising their own goals.

When work is no longer possible for the person with dementia, there may be other ways for them to channel their energy and skill, through voluntary work or contributing to the household economy. Needing to feel purposeful does

not go away just because you have left paid employment. We still have lots to offer and want to feel we are contributing.

Practical ways of helping with obstacles over work and income might be:

- Helping families source affordable and reliable care to cover the hours when the carer is out at work; in our experience this was almost impossible because costs were prohibitive (only a handful of hours being provided by social services) and agencies did not allocate staff for reliable enough periods of time to fulfil contractual obligations of paid employment;
- Helping families source good legal and financial advice early so they can maximise their income and ensure their funds last as long as possible. It is important people are signposted to trustworthy, specialist sources of advice, to those with the legal and financial know-how to give sound advice in a complex situation. The tax and welfare benefits available for younger people with dementia are different from those for retired people, so expertise is needed in navigating the system. Otherwise there is a great danger of lost income that will have a lasting negative impact on a family. Encourage people to claim benefits or apply to occupational charitable trusts to off-set lost earnings, and to apply for discounts to which they are entitled. Several participants in this project only narrowly avoided losing their homes because of problems with money (through lost income or not being able to manage finances).

'I'm sure that keeping a positive philosophical attitude along with daily physical and mental exercise is a key factor in the early stages. We need to be a bit like a chameleon and

adjust ourselves in accordance with our new surroundings. It brings to mind the old saying, “Be like a willow tree and bend with the wind, lest you break”, which is not so easy as I live in Indonesia where people have no idea what Alzheimer’s is or the effects it has on a person’s life. Everyday my wife and I go for a walk together along the road outside of our house. I’ve seen my communication skills diminish but even so I maintain my daily brain activity and stimulation. I also still try to keep some of my old working skills going by making my own bread, baking or decorating a cake. It gives me a great sense of self achievement and satisfaction, none of which comes easy now. I am determined to slow down the effects of the illness for as long as I can to avoid it from totally eclipsing my brain, although I know I won’t win the battle, but that’s not going to deter me from trying.’

(Taken from ‘Barry’s Story’ on the website youngdementiauk.org. Barry has his own website at facesofdementia.simplesite.com)



KEY POINTS

- In the early stages, people with dementia need help to stay well and care for themselves;
- Offering ways to continue with ‘normal’ activities and carry on working if desired is important;
- Help to avoid financial peril is needed.

2.4 Support in the later stages of dementia

As the dementia progresses, family and friends are no longer able to manage without external support. In this chapter we suggest ways of helping that are specific to those of us diagnosed with dementia younger.

'David had a lifelong passion for music. He was a choirboy when he lived in York as a child, and he also played the piano. This passion stayed with him through his life and he was a member of the Police Choir and enjoyed amateur dramatics. He had a beautiful voice. Music continued to be a big part of our lives together after the diagnosis. We had his favourite music playing in the background throughout his final days, which was a comfort to us all. Music also played an important part during his funeral, as everyone who knew him associated him with music and singing.' (Gillian)

Distinctive Issues

Rarer causes – the way in which dementia unfolds differs from person to person, but variety is particularly evident with those diagnosed younger who are more frequently diagnosed with rarer conditions. Those providing care and support need to be aware of the more unusual presentations and feel equipped to respond to cognitive symptoms that are atypical. This means staff having access to specialist training and advice, and regular opportunities for reflective practice.

Disease pathway – another sense in which younger people differ is that dementia is likely

to cause their death, whereas those diagnosed later may die of other conditions and events before they reach end stage dementia. This might mean living many years beyond the point of diagnosis, and, for family members, a large proportion of life spent supporting the person. This project included a carer who had spent 18 years supporting her husband, ending with a painful palliative phase. A carer's health can be adversely affected and many feel the caring role has come to define them as a person.

Specific challenges – being younger has implications for how you respond to cognitive decline. Younger people are fit and strong on the whole, and family members can find it difficult to keep up with their physical activity, especially if they spend much of the time 'on the go', walking around. If a younger person becomes frustrated and hits out, this can be frightening and potentially dangerous for those around (both paid and family carers). Younger people are also likely to be sexually active, and dementia can affect the way we express affection and sexual desire. Awareness and sensitivity in support staff, especially when working with couples, are important.

Qualities valued in caregivers

We were asked to describe our ideal social care worker and came up with a job description:

- Someone with a respectful attitude who treats the person as having thoughts and feelings, and is never patronising;

- Someone who is resourceful and comes up with ideas for overcoming problems and finding nice things to do with the person with dementia;
- Someone who has been carefully matched, who shares interests and outlook (preferably a similar age), and who is willing and able to engage at our level of interest and in the guise of a 'friend' – the worst thing possible is being seen out with a worker in a uniform;
- Someone who comes across as calm and relaxed, with a sense of humour that puts us at ease;
- Someone we can rely on to arrive at the pre-arranged time and not keep us waiting, which causes stress and anxiety;
- Someone who shows kindness and compassion – in our experience this has often been workers who have supported members of their own families;
- Someone who is flexible and does not stick to pre-set tasks and activities, who might be willing to give a bit of help around the house if this is what the carer needs;
- Someone who will stick up for us and champion our cause, helping us fight for what we need and deserve.

'David always had a wave and a smile for people when he was out and about, whether he knew them or not, and they always seemed to respond. I was quite open about his condition and was happy for our carer to be the same. I feel in his own way David did an awful lot to enlighten people in our area about this awful illness and the fact that it is not just confined to the elderly. He is still fondly remembered by people he had never met until this happened to us.' (Gillian)

Support while the person is still living at home

Services aimed at older clients are rarely acceptable to younger people with dementia. We are looking for different models of support in home care, day care and respite provision.

Traditional day centres appear institutional and old-fashioned to younger people. Activities on offer rarely appeal to our age group and the somewhat staid, sedentary atmosphere is off-putting. In this project, attending such a service only worked for those of us who were roped in as 'helpers', and this role had a shelf life as our needs changed. Younger people want to spend their time more actively, getting out and using their energy and skills in leisure pursuits and vocational activities. Some excellent fledgling projects are demonstrating how this can be delivered. Activities can be tailored to the interests of group members. Joining a 'club' is more appealing than feeling you have been 'dumped' in a day service. Family carers are able to relax and enjoy their break if the person with

dementia is attending an activity willingly. New groups are needed – there is a huge gap in the market.

Home care models for older people also need to be modified for younger clients with dementia. The focus needs to be on enabling the person to do as much as possible, to retain their skills and independence. We feel that short visits of half an hour have limited value – longer visits, even of several hours, allow us to plan an outing or fulfil a voluntary role in a local community group. Longer visits also give our caring relatives space for paid work tasks or to spend time with relatives and friends. The home carer assigned to us should be carefully selected as someone with whom we are likely to enjoy spending time, someone with whom we will make a genuine connection. Please ensure continuity of personnel wherever feasible. We feel safe and confident with someone we know and trust, and will be anxious and perhaps resistant if faced with a constant procession of new faces. Who wouldn't?

A final point about the help needed at home is what to do in a crisis. Several families in this project had times of extreme stress, related either to the carer's health or dementia-related changes in the person with the diagnosis. They needed instant help but it was not easy to source emergency support beyond calling an ambulance, which resulted in unfortunate consequences for some. The need for crisis cover applies to everyone with dementia, but can be heightened when the person is strong and, if agitated, liable to do harm to themselves or others.

Support when 24 hour care is needed

We would like to think the option is available for everyone with dementia to stay at home until they die, and this was possible for David, whose story is featured in the final chapter on end of life care. For some families who participated in this project, however, there came a right time to seek full-time care as the dementia progressed. This is never an easy step, and particularly so for families of younger people who know only too well that a specialist local residential provision for younger people does not exist.

Most families prefer to find a local care home where, though it caters mainly for older people, staff are sensitive to the different circumstances and needs of younger people. Experiences of project participants has been encouraging, with stories of excellent residential and nursing home care for the person with dementia and those close to them. Here are some of the elements of support that make a difficult situation bearable:

- Support in reaching the decision to look for a care home and visiting care homes with the person with dementia;
- Friendship and support to cope with the painful feelings associated with the person with dementia being admitted to care permanently;
- Help to find a good pattern of visiting which balances current commitments and acknowledges the future need to rebuild life after caring;
- Support for children and young people who are part of the person's life and may find visiting them in a care home an ordeal;

- Care home staff working in partnership with the family to plan care which recognises the age of the person and incorporates activities that are appropriate to their age and interests – acknowledging they may or may not wish to join in with group activities aimed at older residents;
- Space for intimacy for couples when the person with dementia has a partner who visits.



KEY POINTS:

- Day-care in its traditional form does not suit younger people with dementia;
- Activity-based, outdoor options, which operate as a 'club', are more appealing;
- Home care models need to be adapted to suit younger people – longer visits and a more varied and flexible range of roles;
- Support is needed in finding a care home and settling the younger person, finding ways to sustain the bonds with relatives and friends.

2.5 Examples of projects supporting younger people with dementia

Though few and far between, there are some excellent projects in the UK set up to provide support to younger people with dementia and their families. This chapter lists several.

We are not in a position to endorse these services but are pleased to publicise the pioneering work of organisations nationwide to raise awareness and put in place services geared towards our needs. YoungDementia UK has a growing list of services for younger people on their website and is eager to hear what is happening across the country (see youngdementiauk.org/support-across-uk).

Peaceful Place, Essex (peacefulplace.co.uk)

Peaceful Place is a charity which provides support during the day five days a week with a high staff to member ratio. It serves people with young onset dementia living in Rochford, Southend and Castle Point, Brentwood, Basildon and surrounding areas. Set up in 1996 by Shoebury Baptist Church, the project works closely with the community mental health teams, the memory clinic, social services, Alzheimer's Society and Dementia Advocacy Service. A door to door minibus operates 8.30 to 4.30 and activities include: pool, air hockey and table tennis; arts, crafts and pottery; model making and woodworking; pub games and quizzes; weekly outings and restaurant visits; baking and gardening; live music and guest speakers; life story books and digital reminiscence; singing and dancing; keep fit and Tai Chi; hairdressing

and aromatherapy; pet and drum therapy. The aim is stimulation and to '*enable people to live life to the fullest*'. Peaceful Place also provides advocacy services, support groups for carers and people with young onset dementia, and training on young onset dementia in association with Mindset2 Education and Training.

Manchester Young Onset Dementia Service

In Manchester a young onset dementia service was established in 1996 and was one of the first dedicated services in the country. Anyone who lives in Manchester and was diagnosed with dementia before the age of 65 is eligible to receive support from the service. The service is specifically for younger people because it is recognised that dementia in young people has a significant impact, with people often still working or with young children, and that people are entitled to a service that meets their needs. This health service is provided by Manchester Mental Health and Social Care Trust and runs Monday to Friday. Service users are given the opportunity to meet with other younger people in similar situations in a day service in Central Manchester. Alternatively, depending on circumstances, people may be seen at home. The team consists of a specialist nurse, a social worker and support workers. Service users have a key worker (known as a care co-ordinator) and receive practical help and advice on a range of issues, including planning for the future and assistance with care packages to promote independent living. Families also receive support, should they need it. The service

aims to restore confidence and self-esteem, and to enable people to live with dementia in the best way possible for them. The team works closely with a range of other professionals such as consultant psychiatrists, speech and language therapists and Admiral Nurses, to ensure that people get the help they need.

The service was recently awarded a grant from the Department of Health to develop a dementia friendly therapeutic sensory garden, which has now been completed. The service has also featured on a number of radio programmes, including a four hour live broadcast on Radio 5 Live which aimed to increase public awareness of the issues facing younger people with dementia. The service has close links with other voluntary sector, arts and education providers across the City and aims to provide innovative projects such as music therapy sessions, drama groups and arts based projects. Attendance is time-limited dependent on individual needs and circumstances.

Ty Hapus, South Wales (tyhapus.org.uk)

Ty Hapus is a charity working with the Alzheimer's Society to support those diagnosed with young onset dementia and their families. Ty Hapus offers a day support service in an age appropriate and beautiful environment within a refurbished Edwardian property in Barry, Vale of Glamorgan. Ty Hapus consists of the Halo lounge and dining room, classically and comfortably furnished, and the Moondance Cafe which offers a safe, calm

and comfortable place for people to relax, enjoy activities or socialise with others. There is a Well-Being room with a small hairdressing area where independent therapists can offer guests with dementia treatments and support.

The Forget Me Not Centre, Swindon

The Forget Me Not Centre in Swindon is run by Avon and Wiltshire Mental Health Partnership NHS Trust and exists to help people with young onset dementia reclaim, develop and maintain satisfying, productive and enjoyable lives. Clients take an active part in the success and running of the Centre, so what happens there depends largely on what they enjoy doing or would like to try out. Activities have included hiking, sailing, gardening, DIY, cooking, art, pottery, film making and visits to local places of interest. There is currently a pub lunch group every Friday. Support is offered to families and carers and the Centre also aims to raise awareness of dementia.

Cwmgelli Lodge, Caerphilly

In consultation with the Alzheimer's Society, Seren Group and Gwalia have co-produced (through a review panel of younger people with dementia) a centre of excellence to meet the needs of this community in South East Wales, with 22 units of self-contained accommodation designed as an alternative to traditional care in an older person's dementia care home. As a result of involving people living with dementia, additional features discussed as plans for the centre progressed have included the option for

spouses to stay in partners' accommodation, a potting shed and garden equipment, and a prayer/quiet room. Providing office accommodation for the Alzheimer's Society, the design also includes a pavilion in the garden, a spa for relaxation, a café area and a clinic room.

The Mede, Devon (themede.org)

The Mede was set up to offer holiday accommodation for people with dementia and their families in three self-catering properties in Topsham, near Exeter. It caters for those with limited mobility; personal care, day care, night care, and a sit in service can be arranged, as well as 24 hour respite care. Sallie Rutledge, a qualified nurse, set up the service after supporting her mother-in-law to care for her father-in-law through dementia. Her family's experience was that there is a lack of suitable holiday accommodation where families of people with dementia can enjoy special times together while the carer has some respite. Participants in the Dementia Pathfinders project who stayed at The Mede found it a wonderful, supportive oasis of calm.

Dementia Adventure (dementiaadventure.co.uk)

Dementia Adventure specialise in designing and delivering small group breaks and holidays for people living with dementia and their carer to enjoy together as an alternative to traditional respite. They enable people to get outdoors, connect with nature and continue to enjoy the things they love. Dementia Adventure provide a range of dementia-friendly holidays, including some more physically active walking and sailing holidays, and Bespoke breaks that have included everything from canal holidays to white water rafting. Volunteer helpers accompany many of the trips and full specialist training is provided. As well as holidays, you can also join

regular free park walks implemented by Dementia Adventure in Stroud, Redbridge and Chelmsford. Feedback from participants in Dementia Pathfinders' project demonstrate that this approach can help young adult children of people with working age dementia to stay connected to their parent and enjoy quality time together.

YPWD Berkshire West (ypwd.info)

Younger People with Dementia Berkshire West is an award-winning charity set up to help people with dementia in Wokingham, Reading and Berkshire West which Peter Watson (one of the authors) helped establish. It offers a series of community based workshops that have been designed to provide meaningful activity to the person with dementia in order to provide respite to those in the caring role. Each series of workshops runs for roughly six to ten weeks and aims to support those living with a diagnosis of young onset dementia to learn new and maintain current skills while meeting others in a similar situation and having fun. Examples of workshops in 2015 are: the Harmony Choir which sings songs from the Beatles, Everley Brothers, UB40 and many other bands and puts on gigs; Cut Flowers Gardening Project to sow seeds, grow and harvest; Getting Creative classes in a variety of mediums with trained art workers; walking groups with a short and a long walk and stopping for drinks in a café; Pilates and Meditation to improve posture, muscle tone, flexibility, core strength and joint mobility while also relieving stress and tension. There is also a 1:1 respite service enabling individuals less able or happy to join in group work to access key interests, activities and hobbies. YPWD created the first Admiral Nursing post specifically aimed at supporting families of those with young onset dementia.

Stockport Young Onset Dementia Team

This team is part of Penine Care NHS Trust and

includes a consultant psychiatrist, nurse, social worker and occupational therapist. A recently created post is the Young Onset Social Inclusion Support Worker, known as a YOSI Worker, who can help people access activities in their local community through individualised support. YOSI workers also run small group activities - such as the allotment project, swim group and walking -, with input from other members of the team. The service offers multidisciplinary assessment and treatment and aims to maintain skills through individual and small group activities in the community with the YOSI worker. Examples have been T'ai chi classes, art classes, swimming, dog walking and football. YODEL (Young Onset Dementia Enjoying Life) is a monthly drop in group run in partnership with a local church.

YoungDementia UK (youngdementiauk.org)

YoungDementia UK has developed award-winning services for people in Oxfordshire. It offers individual support where each person is partnered with a trained team member to provide consistent support. People choose how they would like to spend their time during the regular sessions, from long walks to rounds of golf, organising personal paperwork to a visit to a museum. This support enables people to maintain their skills, improving their confidence and self-esteem while creating reliable, frequent breaks for partners and family members. There is a lively group programme providing opportunities to meet with other younger people to enjoy time together, learn from each other and contribute a collective voice on a range of topics. The charity also has a Family Service providing dedicated practical and emotional support through home visits, and regular phone and email contact. There are also get-togethers over coffee, lunch and leisurely walks for families to share their experiences. There are many and varied social events throughout the year, including a monthly

café giving a great night out with good food, live entertainment and a chance to meet with or make friends. YoungDementia UK's website provides a source of information on young onset dementia, and this together with lively social media and networking events beyond the county form part of their work to contribute to a stronger young onset community in the UK.

'I saw my doctor several times before I was referred to the local hospital. I was diagnosed with Korsakoff's syndrome in 2011 in my early 50s. I stay away from the people I used to drink with and I don't have any friends in the small town I live in. My family live 80 miles away and I can't negotiate public transport to visit them. I've tried to explain to the staff at the gym about my dementia. I'm not sure they understand or believe me because I look relatively young and fit. I take a notebook everywhere with me and make lists for things. I cook the same meal every day because I know how to cook it and for how long. I know when to cook it because my cat, Herbert, always lets me know when he's hungry!

'Jen and Simon are my support workers from YoungDementia UK. They are people I can trust and rely on and I've never had that before. It's really nice having someone coming around each week, which is really the highlight of my week, and I'm glad to have someone to chat to. I wish people were more patient and understanding. They make judgements about me based on my appearance. But they should realise that just because people don't fit the stereotype doesn't mean they can't have dementia.'

(Taken from Nic's Story on the website youngdementiauk.org)

2.6 Gillian's reflections on end of life care for David

'My husband David was diagnosed with early onset Alzheimer's at the age of 52. He had just retired from a long and distinguished career in the police force and had been volunteering for the ambulance service prior to working for a solicitor and assisting barristers in the local courts. This he continued to do in various ways for over two years following his diagnosis.

'Gradually over a period of nearly ten years David steadily deteriorated and we adjusted our lives accordingly. In May 2008, after a rather traumatic experience with our local hospital, we were given an Admiral Nurse. This service had only just been established in our area and we were one of the first cases. Over the next two years we had regular visits and were very well supported. In November 2009 our Admiral Nurse approached the local Macmillan Nurses, to see if they would be willing to take on David's case. This they were happy to do and we were assigned the nurse who dealt with complex cases. Over the following months we were lovingly supported by both these marvellous ladies.

'The Macmillan Nurse was in contact with our GP surgery and kept the district nurses in touch with David's condition. On New Year's Eve 2009 we went upstairs to bed as usual but during the night something happened and the next day I could not get David downstairs again. We stayed upstairs for a week until things were put into place for David to sleep downstairs; once a

special hospital bed had been delivered, David was lifted downstairs by paramedics.

'Our dining room became his bedroom and for the first couple of nights I slept on the floor so he would know I was still there. At this point I began having help to get David up, washed and dressed both morning and evening. At first it seemed like an intrusion but I did realise the help was essential. Our usual carer, who had been with us six years, taking David out, continued to visit twice a week to sit with him, which gave me time to shop, meet friends for a quick coffee or get into the garden. This helped me relax a little.

'The Macmillan Nurse approached our local hospice to ask if they would let him have a day in respite care. After visiting us at home they agreed David would be welcome to attend. For the first two visits I accompanied him and explained his routines and capabilities, his likes and dislikes. The hospice staff were very kind and later admitted that their perception of Alzheimer's had changed through meeting David. His smile and gentleness endeared him to other patients who mainly had cancer, and it was humbling to see the kindness they showed him. He often came home with a bag full of chocolate given him by other patients who won at bingo!

'On two occasions we were able to use the Jacuzzi at the hospice. David was gently placed in a hoist which carried him through the air like Peter Pan and he was lowered into the warm

bubbly water where I was waiting for him. A member of staff accompanied us and it was lovely. For a while I was doing something with him and not for him. He was serene throughout and this is now a very precious memory for me.

'In April our Macmillan Nurse had a box of drugs delivered to our house, explaining that though they were not yet needed the box contained everything required for David should he deteriorate suddenly. By now we had a hoist which made it a lot easier for me to move David from room to room to give him a change of scenery. Also, I had a further two visits each day from home carers, one at lunch and another at tea time. He was very unsteady on his feet and could only walk a few short steps and was liable to fall. We were also visited at this stage each week by the district nurse assigned to us, who liaised with the Admiral and Macmillan nurses. They made a good team and I felt I could rely on them completely.

'Just after my birthday at the beginning of June the Macmillan Nurse told me she had observed pain in David. She gently explained that it was time for him to stay in bed on a morphine syringe driver. At the start of the treatment he reacted very badly and I thought he was dying before my eyes. Even though he calmed down quickly it was shocking and distressing.

'The next day our Macmillan Nurse called again and talked me through what had happened. She

sensitively explained that there was a possibility David would die that weekend. She guided me through what to do, telling me to call the out of hours district nurses who would deal with the situation as David was logged as an expected death. He did not leave me that weekend and valiantly carried on for another two weeks.

'During this time we had a daily visit from the district nurse to top up the morphine and add drugs to assist breathing and dry up secretions on the lungs; these helped but did not alleviate the problem completely, and the sound was at times distressing. On two occasions I was so worried I called the out of hours services and the nurses visited us at home. They reassured me everything possible was being done, commenting on the high standard of my care of David. This I appreciated greatly, as it was easy at times for me to doubt I was getting it right.

'Also calling daily now were the end of life team, who came in three times a day – once in the morning, then at lunch time, and again late afternoon. My usual girls doubled up and came in the evening, staying a little longer to keep me company and enable me to shower and wash my hair. Our box of drugs was topped up by regular deliveries from the local chemist who kindly opened the front door and left the package inside in case we were sleeping. I would wiggle onto the bed with David sometimes; it was a struggle, but where there is a will there is a way!

'Each morning, when David was being washed, I also had his sheets changed. The team teased David that it was like a five star hotel. He was long past understanding, but I was glad they included him in all our conversations and were interested in his life before the illness. By now he was not eating and it was shocking to see how quickly he lost weight. It was distressing to see my lovely 6ft, handsome, athletic husband reduced to a painfully thin shadow of himself. I thought David had a chest infection due to his noisy breathing at one point, and also noticed he had oral thrush and worried this may have been caused by the fruit smoothies which he loved; our GP practice responded to these issues.

'I had always been adamant that David would stay at home until the end, but about now I began to doubt that I was giving him the care he so deserved. Our Macmillan Nurse explained that nothing different would be done elsewhere, but the hospice had said they would give David a bed for end of life care if I wanted. Once I knew nothing would be any better for him, I was okay to carry on. She also explained that everyone involved would keep supporting me as they felt it would be a shame for me to hand over the baton so close to the end. I was really pleased to hear this, as I feel it would have affected me far more later on if we were not at home for the end.

'Just over two weeks after David first become bedbound the end did come. On the Friday I really thought he was going to leave us, his breathing was so loud and laboured, and we had a long and anxious day followed by a long and anxious night. On the Saturday (26 June) I think everyone involved in his care was surprised he was still with us. That morning I held his hand and told him how proud I was of him and how much I loved him, and that it was okay for him to go, that I understood he had had enough. I really

wish I could say that his end was peaceful but it was not. He kept on struggling to breathe and looked so frightened, until finally he breathed his last breath in my arms. He did however die at home, with me by his side, together with our much loved cats who would not leave his room for the last couple of days. The doors to the conservatory were open, as was the door to the garden. The sun shone in and we could hear the birds singing their hearts out. David always loved the great outdoors and wildlife so it was wonderful to be able to do this for him.

'The district nurse took care of everything. She took away the drugs box, advised people involved in his care that he had died, and contacted the undertakers of our choice. When they came to take David away it was so hard. Walking to the door and watching David being gently laid into the back of the vehicle they used was painful, and indeed each time I opened the door for months after this the memory would come flooding back.

'The next week is a blur, as you have so much to do. Some people think that if you know it is going to happen it somehow makes it easier. IT DOES NOT. Just before the funeral the equipment we had used was collected by the hospital services department. It was quite a while before I could use the room as a dining room again, preferring to eat at the breakfast bar in the kitchen.

'I was well supported by friends and our wonderful Macmillan Nurse called to see me until well into the New Year. The Admiral Nurse was in touch for over 18 months and this was invaluable. I was able to talk over aspects of David's death that caused me anguish. Our Macmillan Nurse explained that it was the first time they had supported a younger person dying with dementia at home and they had learnt a

great deal. This was a comfort as David liked to help others. Unusually the only entry on David's death certificate is Alzheimer's, whereas in older people another condition is usually named as responsible for death.

'My Admiral Nurse was very intuitive in that she recognised that not only had I lost my beloved husband but also my entire way of life. As the weeks passed I found it difficult to put myself to anything. Even going out was a problem. Shopping for food was difficult, with only one to cater for, but the most difficult thing was the silence. When I was out it was difficult coming home now that David was no longer there. After all the comings and goings everything just stopped. Even with Alzheimer's, our bond became stronger and closer. I would not go back and change anything (only the things I felt I or others could have done better). First thing in the morning until last thing at night David was constantly on my mind. I saw him walking in our local park when I went for a walk (we often went together). I talked about him often, even though it made some feel uncomfortable. At first it would make me teary, but after a long time I could talk about David without the accompanying waterworks. If I am honest, grieving is a never ending process. It just gradually changes as you progress. A small thing is usually the one that gets my eyes watering again. The first anniversaries of things like birthdays, Christmas, date of dying and many more were especially difficult. I have now learnt that it is only that day that is so bad, and it is better the next day. I smile about a lot of things that used to make me cry and now cherish my happy memories.

'Some memories of unfair treatment still hurt, like the time David was reassessed for NHS continuing care funding towards the end of his life. The assessor said that, as David was so ill now, his needs were easier to meet and he did

not require any specialist care. Our specialist nurses were present and nearly exploded at this point, saying their support was very much needed in David's case. It was obvious to us all that the payments were going to stop. It was upsetting as it seemed that David was not deemed worthy of this help after working all his life and getting an illness he had no control over. The payments were irrelevant, it was the principle and the manner in which the assessment was done that distressed me. It was me who had provided the bulk of care, and still did.

'A couple of years after David's death, through our Admiral Nurse, I started some voluntary work, which I enjoy immensely. It involves the support of people with dementia and their carers, as well as working with older people with mobility problems at a Falls Clinic. Each week I now have a routine and enjoy working with people of different ages.

'In the five years since David's death it has struck me that much has changed regarding younger people with dementia. It is more widely talked about and it is recognised that the needs of younger people are very, very different.'

Useful organisations

ALZHEIMER'S SOCIETY

Helpline: 0300 222 11 22

Email: enquiries@alzheimers.org.uk

Online forum: Talking Point

Website: alzheimers.org.uk

Alzheimer's Society has a helpline and many useful factsheets to order or download from their website, including several on young onset dementia and rarer conditions. Their online forum, Talking Point, has an area for people affected by young onset dementia, and Dementia Connect lists local services, some of which are aimed at younger people.

www.alzheimers.org.uk/Younger_People_with_Dementia.

ALZHEIMER SCOTLAND

**24 hour freephone Dementia Helpline:
0808 808 3000**

Email: helpline@alzscot.org

website: alzscot.org

The national charity for dementia in Scotland, as well as a freephone helpline, Alzheimer Scotland has a search facility on its website to enable you to find help in your area.

CJD SUPPORT NETWORK

Helpline: 01630 673973

Email: cjd.support@cjdsupport.net

Website: cjdsupport.net

This is a patient support group providing help and support for people affected by all strains of Creutzfeldt-Jakob disease, with a helpline offering counselling and support, and a website with information through useful factsheets.

DEEP (DEMENTIA ENGAGEMENT AND EMPOWERMENT PROJECT)

INNOVATIONS IN DEMENTIA

Email: Rachael@myid.org.uk

Telephone: 01392 420076

Website: dementiavoices.org.uk

A UK-wide network of groups for people with dementia seeking to influence public policy and awareness of dementia locally. Younger people with dementia are strongly represented in these active forums.

DEMENTIA UK – ADMIRAL NURSING DIRECT

Email: direct@dementiauk.org

Telephone: 0845 257 9406

Website: dementiauk.org

A national helpline provided by experienced Admiral Nurses who are specialists in dementia support, DIRECT operates every weekday, plus Wednesday and Thursday evenings. You can also find out if there is an Admiral Nurse service in your area.

FRONTOTEMPORAL DEMENTIA SUPPORT GROUP

Website: ftdsg.org

This support group incorporates alcohol related dementia and primary progressive aphasia as well as frontotemporal dementia (also known as Pick's). FTDSG runs regular carers meetings and seminars, as well as holding useful information on its website along with details of regional contacts. It has a newsletter which can be emailed or sent in the post.

ST GEORGE'S UNIVERSITY HOSPITALS NHS FOUNDATION TRUST

COGNITIVE NEUROLOGY AND DEMENTIA SERVICE

Website: www.stgeorges.nhs.uk/service/neuro/neurology/cognitive-neurology-dementia/

The Cognitive Neurology and Dementia Service at St George's Hospital in South West London provides a consultant-led multi-disciplinary approach to the diagnosis, assessment and treatment of all cognitive disorders, especially rare forms of dementia which can be more difficult to identify and present more commonly in younger patients.

EARLY ONSET DEMENTIA SUPPORT GROUP

Website: www.youngdementiasupport.london

The Cognitive Neurology Service offers a support group for younger people with dementia and family members. Evening meetings are

held every 6-8 weeks at St George's Hospital in partnership, currently, with Dementia Pathfinders.

A website was launched in July 2015 providing information about many aspects of life with dementia as a younger person, for example: getting a diagnosis; rights at work; driving and dementia; benefits and financial support. In addition, the website provides links to websites for the London boroughs falling within the catchment area of St George's University Hospitals NHS Foundation Trust: Croydon, Kingston-upon-Thames, Merton, Richmond-upon-Thames, Sutton and Wandsworth.

SOCIAL CARE INSTITUTE FOR EXCELLENCE – DEMENTIA GATEWAY

Website: scie.org.uk/publications/dementia/living-with-dementia/young-onset-dementia

SCIE's interactive e-learning tool on dementia, Dementia Gateway, has modules on young onset dementia aimed at the social care workforce, including films where people with young onset dementia talk about their experiences.

RHAPSODY – RESEARCH AND STRATEGY FOR DEMENTIA IN THE YOUNG

Website: rhapsody-project.eu

A European project in the UK, Netherlands, France, Germany, Portugal and Sweden to improve care for people with young onset dementia by supporting their carers, the goal is to produce a skill-building e-learning programme for family carers.

YOUNGDEMENTIA UK

Email: mail@youngdementiauk.org

Website: youngdementiauk.org

Telephone: 01993 776295

An Oxford-based charity set up in 1998 as The Clive Project, as well as running a Club and One to One Service for people with young onset dementia in Oxfordshire, and a Family Service, it provides the steering group for the National Young Onset Dementia Network, enabling younger people to have a voice nationally. Its website is a useful source of information about living with young onset dementia and the services across the UK set up to meet their needs.

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