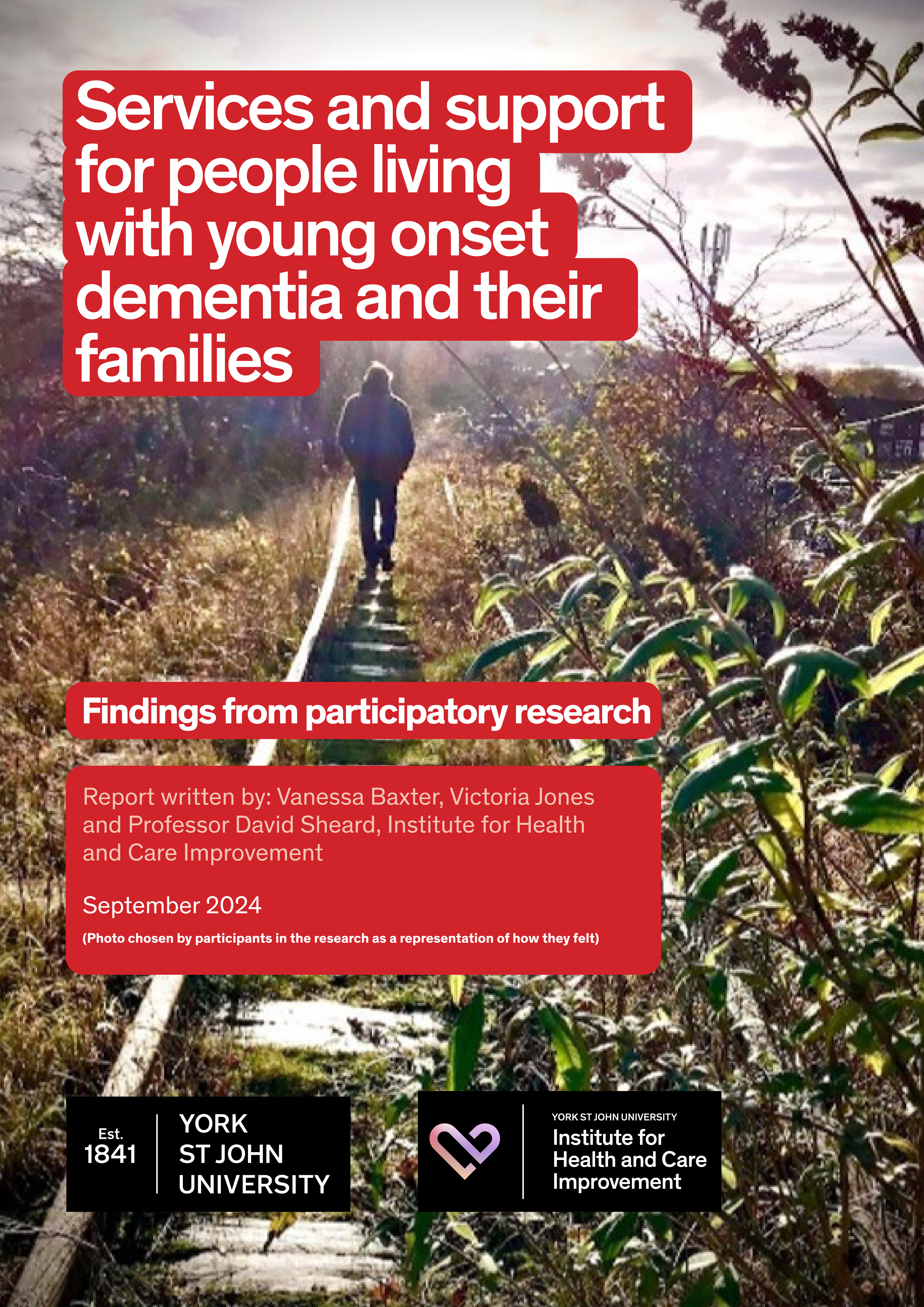

Services and support for people living with young onset dementia and their families

Findings from participatory research

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(Photo chosen by participants in the research as a representation of how they felt)

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Acknowledgements

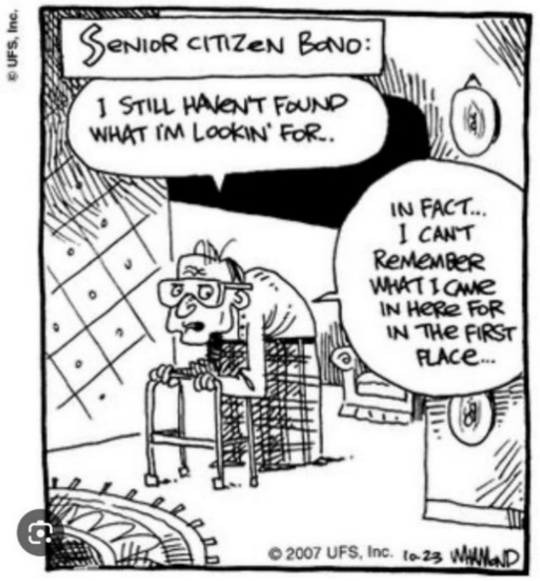
Our sincere thanks go to everyone who generously gave their time to take part in the research, most especially people living with young onset dementia and their family members. We would like to give deepest thanks to Jackie Crewe from Dementia Forward for all of her help and support in recruiting participants for this research, plus organising venues and refreshments to make it a more sociable event for those attending. We would also like to thank all of the Dementia Forward members of staff who supported participants during the research groups.

Dementia Forward supports people living with or caring for someone with dementia in North Yorkshire and York. If you have a diagnosis of dementia or are concerned about memory problems, please call its Helpline for free, confidential information, support and advice and to be connected to a local Support Advisor. It also runs wellbeing groups and activities, including Brain Health Cafes and Hub Clubs (person-centred day services) and provides specialist support and activities for younger people affected by dementia. You can find out more by calling the Helpline on 03300 578592 or visiting www.dementiaforward.org.uk.

Background

This research project aimed to understand more about the services and support that people living with young onset dementia need.

We undertook participatory research using the Photovoice methodology with 4 people living with young onset dementia and 8 family members, at 4 locations across North Yorkshire, to understand more about their experiences of services and support, looking at what is available, what they use and what they would like, including gaps in what is available.



Not just Elderly!!
Not just Memory!!

Headline findings

- People living with young onset dementia want to do a variety of activities, and those recently diagnosed appear to need to find more to occupy them than they do currently.
- Activities need to be age appropriate, not “dumbed down” and “normal” things that people living with young onset dementia would have done prior to their diagnosis. There are several examples of activities that are well delivered.
- Activities cannot be a “one size fits all” offer but need to be flexible and fitted to the person rather than the person being fitted to the activity.
- Facilitators for support and activities need to include making it easy to find information about potential activities, having a ‘meet and greeter’, providing a befriender or supporter to accompany the person, offering a transport option, and having dual activities in the same place at the same time for both carers and the person living with young onset dementia.
- People diagnosed with young onset dementia who live alone (in contrast to those who are part of a couple) require much more support, including someone to take them out and accompany them to activities.
- Carers acknowledge that their lives are now very different to what they had planned or envisaged for the future, with the distance between them and their family member/loved ones increasing as dementia advances. However, looking after carers enables the carers to look after the person living with young onset dementia.
- Peer support was valued by carers, for social interaction and moral support as well as being able to discuss issues and sharing information, experiences, hints and tips, but it appears as though not all areas of the county have carers’ groups.
- Carers need more than an information book to read, but someone to support them personally, listen to them, understand their circumstances and help them with what they are going through. It would be helpful to have a flowchart or checklist of steps they need to take, the order in which to do them and how to do them or who to contact.
- Carers need a “buddy” - either a professional or a peer - to help them navigate the steps, and/or a ‘one-stop shop’ to support both the carer and their family member/loved one with relevant, tailored and expert support.
- Carers of people who had received a diagnosis recently were not aware of the support and advice available to them from Dementia Forward.
- All carers were frustrated about the time-consuming paperwork required and would appreciate someone to help them through the systems and processes: these should be more joined up across different public sector organisations.
- For most, there was little to no follow up from the Memory Service, GP or other medical professionals after the diagnosis.

Recommendations by the research team

The actions recommended by the groups were very clear, with many groups asking for similar things. As a result we would recommend a number of actions: not all of these recommendations are applicable to Dementia Forward but the organisation could potentially act as an advocate for them.

Since many of the themes from this research echo the desk review findings, it could be helpful to investigate further why these themes are still arising and why families do not perceive them to have been tackled. Some of the recommendations may already be in place or have been acted upon and therefore further work is needed to understand why participants feel they are either unaware of available support or have not been reached out to.

Provision of activities

- Create a directory of the activities available in each area, available in paper format and as an online searchable database, together with explanatory staff support if required.
- Consider how activities can be provided that are age appropriate, relevant to individuals' specific interests and flexible enough for all types, experiences and phases of young onset dementia. These activities should have somebody to "meet and greet" participants.
- Seek to ensure equality of activities available in each geographical area.
- Service design needs to be more person centred and more innovative. Consider how to match people living with young onset dementia with a variety of meaningful activities to suit their individual interests (such as sports, animals, walking or music), and replicating an activity such as Golf in Society for other sports/activities.
- Consider whether it is possible to tap into the existing provision of 'befrienders' (such as PAs for people with learning disabilities) to accompany those living with young onset dementia to places/ activities they want to do.
- Offer a transport option alongside any service provided.
- Look at lessons that could be learned from what is offered by other hubs such as Sage House in West Sussex (for all people living with young onset dementia and their families) and the Leveson Centre in York (which aims to be a centre of excellence supporting cancer patients, friends and families), such as the provision of activities and support in a dedicated and pleasant environment, peer buddies and a restricted Facebook group for questions and advice.

Supporting carers

- Ensure that all carers and people living with young onset dementia, even before they have a diagnosis, are given contact details for Dementia Forward and have access to a Dementia Forward Advisor: this does not seem to be happening automatically and all entry points to the Dementia Forward support pathway need to be facilitated. This includes ensuring support is provided for those who would not ask for help.
- Ensure that Dementia Forward advisers make it clear in their introductory or follow up contact that they can signpost carers and people living with young onset dementia to groups, activities or support.

- Offer continuous access to support, with follow up after diagnosis, so that carers do not get to a crisis before they get extra support.
- Ensure the provision of face-to-face carer support groups in every geographical area, with the option of activities for the family member/loved one. Set up a support group or way to connect specifically for carers of people with frontotemporal dementia or other types of dementia that may have very specific presentations.
- Introduce a buddy system of peers.
- Set up a restricted access Facebook page for peer support and responses to questions.
- Provide training for carers on coping strategies and seeing things from their family member/loved one's perspective and/or investigate why details of the training already provided by Dementia Forward may not be reaching newer carers.
- Provide advice/education on how to stop/block scammers.
- Develop the provision of respite on an ad hoc basis, as well as a regular service.
- Develop the provision of care homes for younger people living with young onset dementia.

Information needs

- Ensure that carers have access to information in the time leading up to the diagnosis.
- Consider working with the Memory Clinic to provide information that is specific to young onset dementia (rather than dementia generally) and tailored to the type of dementia.
- Look at different ways in which to provide information, including options for a personal contact to check in with people and ask how they are doing, 1:1 chats (for example talking informally about the next steps to take but followed up by information sent via email), or an advocate/ supporter.
- Investigate developing a 'Say It Once' style website so carers do not need to provide the same information to every different organisation.
- Provide a checklist about what to expect or do at each part of their journey – do x then y then z – with resources available for each step and what different people can do to support each step.
- Provide information on coping strategies and how to deal with different scenarios, tips on ways to approach things and talk to the person living with young onset dementia, and legal and financial rights and processes.
- Consider developing information for other family members on what is happening and how to support and interact with the person living with young onset dementia.

Healthcare support

- GPs should acknowledge that they've taken over care of the person, with a handover from one service to the other.
- GPs should be prompted to offer a regular/annual check up and review of medication.
- All GP surgeries should become dementia aware and have a designated member of staff for dementia and/or a dementia clinic.
- Consider ways in which to improve awareness and empathy within the health service.
- Remove the artificial barrier of services only being available to those who are over 65 (e.g. care homes, counselling).

Supporting carers

- Consider whether people and families who are from ethnic backgrounds other than White, who are not heterosexual or who have other protected characteristics may require more tailored services and support.
- Raise general awareness and understanding of all forms of dementia by the general public.
- The Government needs to clearly lay out legal rules on capacity and other legal obligations/rules to comply with.
- Raise the issue of being unable to obtain a testamentary capacity assessment with the Government.
- Increase awareness of the "Just Can't Wait" card, including how to get it.

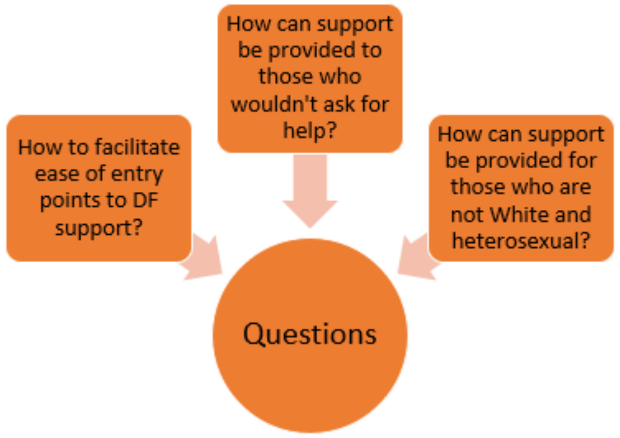
What could a hub for young onset dementia look like?

Activities for people living with YOD

Directory of activities available in each area, with support from DF staff to navigate

Access to "befrienders" for 1:1 support to access activities

- Age appropriate
- Relevant to individuals' specific interests
- Flexible for all types and stages of YOD
- Transport options
- Meeters and greeters
- Replicate Golf in Society for other sports/activities

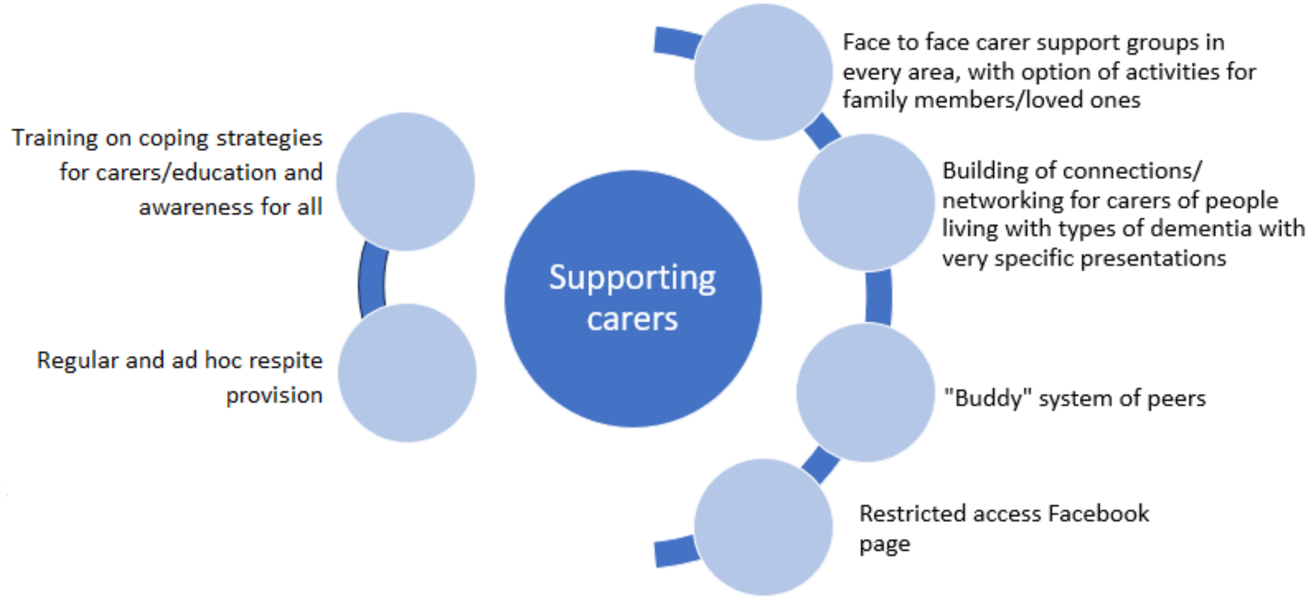


Questions

How to facilitate ease of entry points to DF support?

How can support be provided to those who wouldn't ask for help?

How can support be provided for those who are not White and heterosexual?



Supporting carers

Training on coping strategies for carers/education and awareness for all

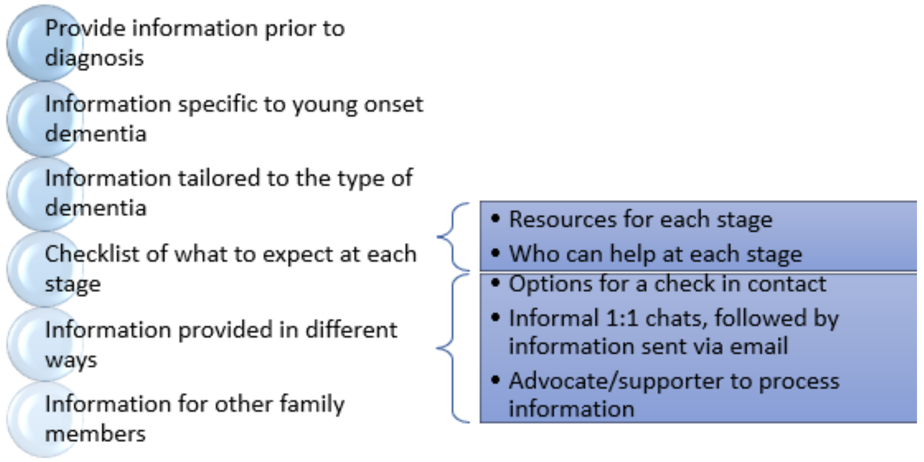
Regular and ad hoc respite provision

Face to face carer support groups in every area, with option of activities for family members/loved ones

Building of connections/ networking for carers of people living with types of dementia with very specific presentations

"Buddy" system of peers

Restricted access Facebook page



- Provide information prior to diagnosis
- Information specific to young onset dementia
- Information tailored to the type of dementia
- Checklist of what to expect at each stage
  - Resources for each stage
  - Who can help at each stage
- Information provided in different ways
  - Options for a check in contact
  - Informal 1:1 chats, followed by information sent via email
  - Advocate/supporter to process information
- Information for other family members

Empty room, empty life

There's nothing going on in his life, his life is empty

He needs to fill the space with something that he enjoys doing

Treated like rubbish

They feel like they've been put on the rubbish pile

We're being treated by others like rubbish, with no ongoing support

Solve the basics and develop proper support, rather than just funding medical research

This is also somewhere to put the reams of paper we get given!

Stuck within four walls

She spends too much time on her own

It's not healthy for her

Age appropriate!

Not being treated like children

Activities offered need to be age appropriate and relevant to each person's ability, something that challenges and stimulates them

“It's an insult to dumb down activities”

In an ideal world everyone is so different: dementia has different stages and presentations

Animals mean a lot to us

They're a focus and purpose in life
I get to go out more, I enjoy being outside
It's time for me, independence
She enjoys walking the dog and it gives her good company, self-worth, time away from me. He's calming to pet and affectionate

Golf in Society is a great example of what works – a positive experience

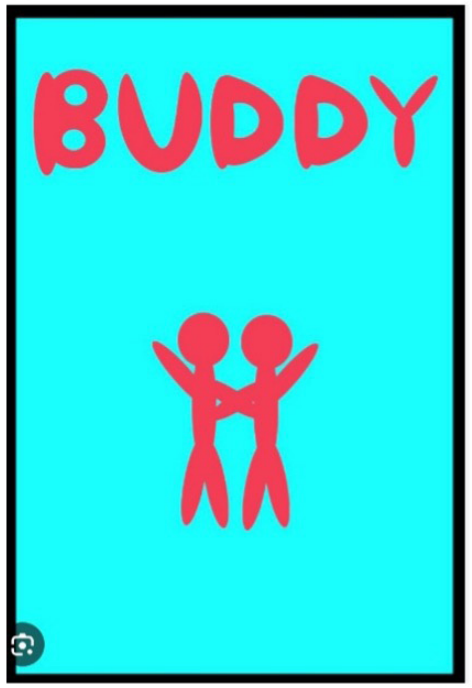
It gives me an opportunity to play golf with others, supported by the volunteers/coaches to help us along

There's no negatives, they just support us to play. They're all positive, positive, positive

I know he'll have a wonderful two hours, it ticks all the boxes for both of us

Having a buddy or companion to do things with

I want to do things that I enjoy, but I can't get there on my own
A companion able to spend time with her and take her to places
Someone to stop her being on her own all week
Someone to talk to and do things with

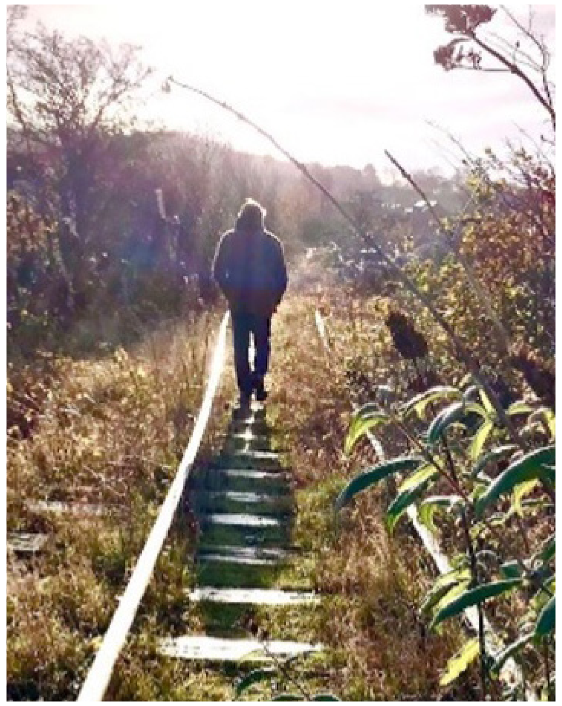


Transport is essential

Lack of transport signifies isolation and no ability to still engage with the world
Having transport means support and socialising with people in the same position in their own peer group
Transport needs to be provided alongside any services

Carers feel lonely and sad

“I’m walking away and losing my loved one”



This is the distance between the person I knew and the relationship I had, they’re getting further away

It’s about what we need to allow us to care, if we can look after ourselves

People don’t appreciate the work I do to enable my loved one to have a good life

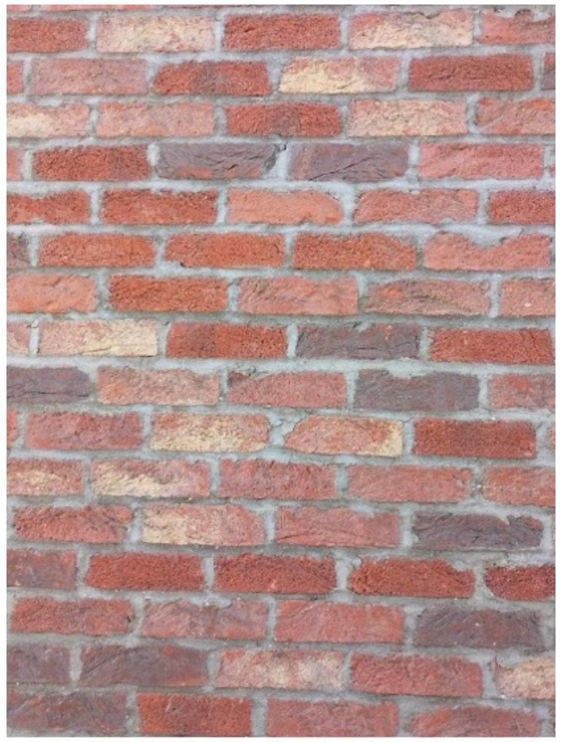
Not enough time!

I don’t have enough spare time during the week to focus on her, as I work full time

Public organisations don’t make things easy for us and you have to hunt for everything, they need to simplify things

Why can’t there be something like the ‘Say It Once’ website for people who have been bereaved?

Finding anything out is like banging my head against a brick wall



I’ve taken the initiative and done everything myself as no one will do things for us

Improve the attitudes of public sector organisations – it seems like they want us to fail

Why do we need to jump through so many hurdles and apply for things in so many different ways? Why isn’t there a joined up system?

We need training

As a carer: What do I do? How do I do it? What do I need to know?

Help me to understand - the more information that is available, the easier it is to support the person

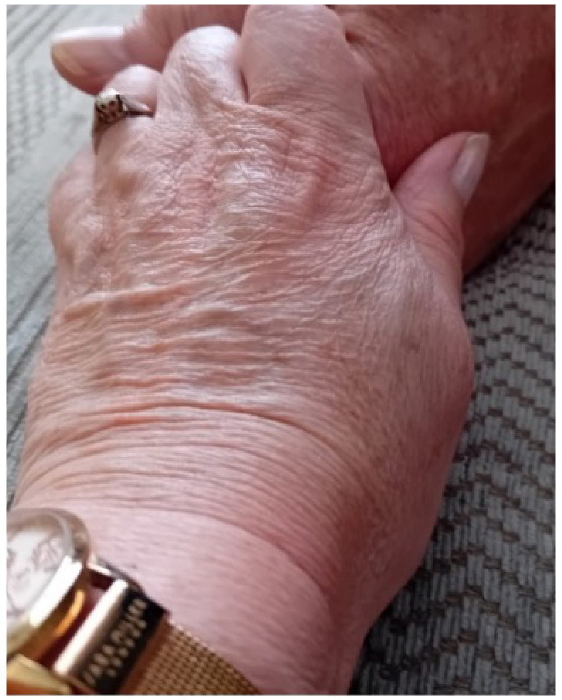
I don’t want to unintentionally make someone feel bad if I say or do something wrong, I need to keep the other person there in mind

Having a buddy

We need personal support as well as professional support

It would be good if we could have a buddy

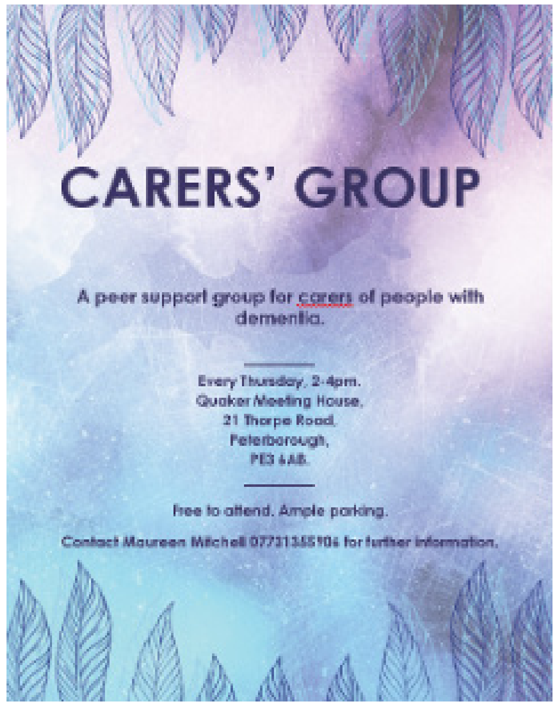
Someone to talk to that knows what we're going through



Peer support for carers

We need to interact with other carers – for social interactions and learning from each other's experiences

Hints and tips from others are really important



CARERS' GROUP

A peer support group for carers of people with dementia.

Every Thursday, 2-4pm.
Quaker Meeting House,
21 Thorpe Road,
Peterborough,
PE3 6AB.

Free to attend. Ample parking.

Contact Maureen Mitchell 07731355106 for further information.

We want a one stop shop from professionals

Not being passed from pillar to post or signposted elsewhere!

We need someone with the appropriate knowledge about next steps, rather than us having to navigate the system alone

Relevant, tailored, expert support for all types of young onset dementia

We need a professional, a buddy and a checklist that's relevant to the diagnosis, not having to plough through lots of paper

Doctor's Surgery

Ask for an appointment, don't just expect it to happen – don't leave it to chance!

It can take a long time to get anywhere

Everything seems to stop when you get handed over to the GP from the Memory Service – we need to be held and supported from one service to another

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