

Working together to support children and young people affected by parental young onset dementia

Hannah Gardner

Consultant Admiral Nurse
for Children and
Young People

Dementia UK



Patricia Masterson-Algar

Research Fellow
Bangor University

19th November 2024

Content

- Who are **Young Dementia Carers?**
What do they need?
- Consultant Admiral Nurse for Children and Young People
- Developing resources: **iSupport for Young People**
- Working together **to improve support initiatives**

Who are Young Dementia Carers (YDCs)?



Masterson-Algar et al. 2023 – IJERPH





They are **children and young people** who help care for a family member living with dementia

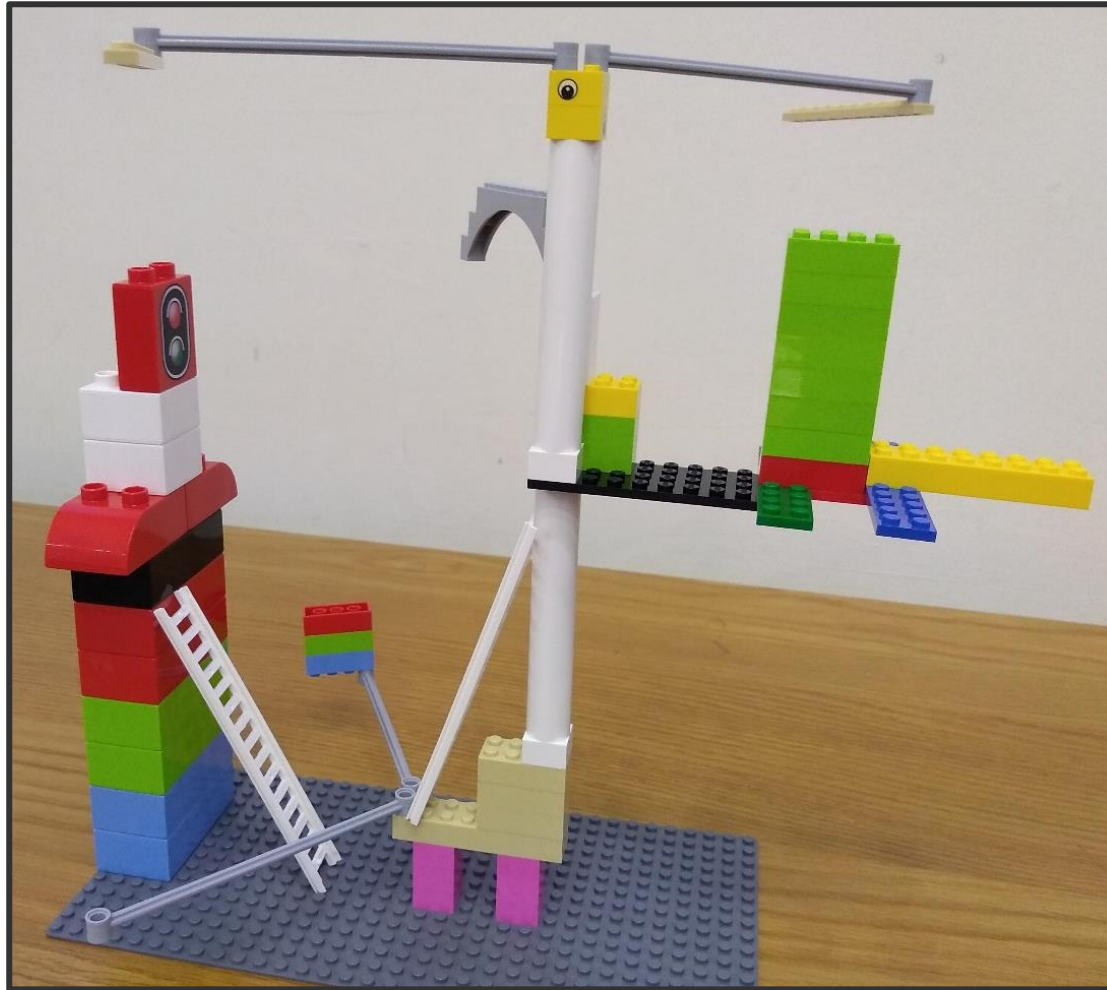


Evidence shows

- **YDCs rarely receive appropriate training and support**
- **Their visibility and identification is dangerously low**



"My life, a balancing act"



Masterson-Algar 2020

Qualitative Health Research - <https://journals.sagepub.com/doi/10.1177/1049732319900498>



What have families and professionals told us?



Masterson-Algar et al. 2023 – IJERPH

Tailored support that is 'fit for purpose'



"I've never found that right place for them. What they were offered were things like trips out, and although they love all that sort of thing, my girls didn't particularly need that, **they needed someone to talk to"**

Parent of YDC

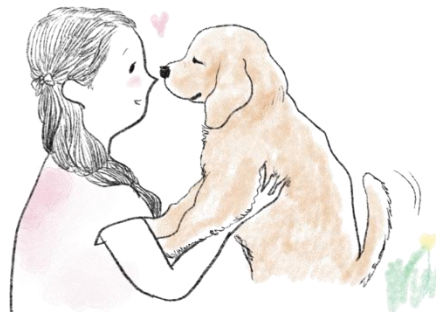
The 'power' of peer support

"Our children felt unusual, isolated and alone. So being with other people who are in a similar situation, is really, really powerful"

Parent of YDC

"In that group there's a universal understanding, so you don't have to do the explaining part"

Young Adult Carer





WHAT DO YOUNG DEMENTIA CARERS NEED?



1 SOCIETY to UNDERSTAND

- ✓ Being a 'young carer' can mean many different things.
- ✓ Dementia in the family can impact all aspects of a young person's life.



5 TAILORED SUPPORT 'FIT FOR PURPOSE'

- ✓ PEER SUPPORT- A chance to talk
- ✓ Available 'as and when needed?'



- ✓ Specialist nurses (e.g. Admiral Nurses in the UK)
- ✓ Online & face to face



4 AWARENESS CAMPAIGNS that RESONATE with US

- ✓ Designed by us!



3 SUPPORT for the WHOLE FAMILY

- ✓ Dementia affects all members of the family



2 CLEAR IDENTIFICATION PATHWAYS

- ✓ Young people's services
- ✓ Adult services



Consultant Admiral Nurse for Children and Young People

19/11/24



Consultant Admiral Nurse for Children and Young People

Launched in June 2024

National role dedicated to **all under
18 years olds** living within families
impacted by dementia

Why has the role been introduced?

No service specially for children and young people
nationally or **internationally**


- Platform to raise awareness
- Combat loneliness and isolation
- Increase knowledge and understanding
- National recognition, resources and support
- Young people driving the service



Clinical support

- Improve comprehension and knowledge
- Improve well-being and coping strategies
- Emotional support
- Listening

**Only 25% of my time is dedicated
to clinical support**



**Dementia UK
Admiral Nurse**
identifies child or
young person
needing support

Leadership



Ambassador for Children and Young People



Driving best practice



Identify gaps in support



Raise awareness within education, social and healthcare settings



Influence Policy and Research

Common needs identified

Acceptance

**Emotional
impact**

**Understanding
coping**

Sharing impact

**Maintaining
relationship**

Own future

Isolation

**Education and
social life**

Care environments

Loss and grief

**Supporting family
members**

**Transition into
legal adulthood**

Challenges

**Hidden and
hard to reach**

Categorising

**New
Dementia UK**

**Data
protection**

**Lack of
research and
local support**

**Supporting
virtually**

Safeguarding

Age range

**Young onset
dementia**

Consent

Research opportunity



Bangor University



Dementia UK Research and Publications Team



Journals and articles



Collecting service delivery data

Personal reflections

30 young people supported

Mostly young onset dementia families

Work alongside Jules Knight,
Consultant Admiral Nurse for
Young Onset Dementia

Complexity

Maturity

Risks

Support well parent

Listening

Education gaps

Empathy not pity

Voice behind education

Opportunity

Developing resources: iSupport for Young People



What is iSupport for Young People?



www.isupportdementiacarers.co.uk

iSupport for Young People

- An adaptation of iSupport
- Aims to:
 - ✓ Support the mental health, knowledge, and skills of **YDCs**
 - ✓ Help service providers improve the support they offer



Masterson-Algar et al. 2023 IJERPH

iSupport for Young People

MODULE 1

Introduction to dementia

What is dementia and how does it affect someone

MODULE 2

Being a carer

The journey together
Improving communication
Supported decision-making
Involving others

MODULE 3

Caring for me

Reducing stress in everyday life
Making time for pleasant and meaningful activities
Thinking differently

MODULE 4

Providing everyday care

Eating and drinking - preventing health problems
Eating and drinking - more pleasant mealtimes
Toileting and continence care
Personal care
An enjoyable day

MODULE 5

Dealing with behaviour changes

Introduction to behaviour changes
Memory loss
Aggression
Depression, anxiety and apathy
Difficulty sleeping
Delusions and hallucinations
Repetitive behaviours
Walking and getting lost
Saying the wrong thing at the wrong time
Putting it all together





Information about dementia and how it can affect people

Dementia has stages

Dementia symptoms can range from minor difficulties with thinking, learning, language or small changes in personality to severe difficulties that make it impossible to manage daily activities without help. It can be helpful to view dementia as a series of stages to understand the illness. However, it is important to understand that not all people with dementia will have all symptoms and some of the symptoms may only appear at one stage of the disease.

In the early stage, people with dementia may have memory problems, become disoriented with respect to time, lost in familiar places and show difficulties making decisions.

As dementia progresses to the middle stage, people with dementia may become very forgetful and in need of help with daily activities such as shopping, dressing, and washing.

In the late stage, people with dementia may not recognise relatives or friends anymore. They may display changes in behaviour that can be upsetting and distressing to the person with dementia and those around them.





**It includes caring tips
and advice on getting
help and support**

2. Types of help and support that you might need

First let's look at a few examples that relate to you or maybe someone in your family:

- **Leah** is 14, she cares for her dad who has dementia every day after school and during weekends when her mum needs to go to work. She receives no help and feels overwhelmed. She would like to get some help from others.
- **David** takes care of his wife who has dementia. David has involved his two teenage sons in the care. The brothers regularly take their mum out for walks or help clean the house and prepare meals.
- **Fatima** is 15 and helps care for her grandad who has dementia. Fatima receives help from her school if for example she is struggling to submit her homework on time. She also feels supported by her friends and some of her teachers who listen to her when she is feeling a little bit sad and is struggling with her grandad's memory loss.





Examples of real-life scenarios

4. Doing pleasant activities together

Doing the things you love is very important. It can be very rewarding to do some of these things with the person that you help care for. However, it might be difficult at first to think of activities that are nice and suitable for both of you.

In this exercise we will make a list of the pleasant activities that you can do with the person you help care for.

Let's look at an example:

Dion and his brother help their mum take care of their dad who is living with dementia. During the weekends to give their mum a rest, the brothers go for a long walk around the neighbourhood with their dad. They then sit in their favourite park to have a drink. The brothers enjoy the walks and their dad also benefits because he is able to get some exercise and fresh air.





**Activities to help
young people reflect
on their own situation**

Which pleasant and meaningful activities would you like to do?

Once you have some time for yourself, it can be hard to think of the things you would like to do. There are many possibilities and even in a short amount of time, you can still do an activity that you like.



1. Activity



Please check at least two activities that you would like to do more often. If your favourite activity is not listed below, use the 'other' box to write your own activity.

- | | | |
|--|--|--|
| <input type="checkbox"/> Listen to music | <input type="checkbox"/> Do sport | <input type="checkbox"/> Go shopping |
| <input type="checkbox"/> Watch TV | <input type="checkbox"/> Do crafts | <input type="checkbox"/> Go for a walk |
| <input type="checkbox"/> Spend time with friends | <input type="checkbox"/> Read | <input type="checkbox"/> Other: <input type="text" value="type here"/> |
| <input type="checkbox"/> Go to the cinema | <input checked="" type="checkbox"/> Exercise | |

UK and international collaborations



CPD Course: An Introduction to iSupport for Young People



Working together to improve support initiatives

▪ Workshop: 12th November, Manchester



▪ Developing a Peer Support Programme

- Funding application submitted (£225,058)

To sum up

- **We have made progress!**

Awareness about YDCs is increasing but there is still a lot of work to be done!

- **Dementia UK and Bangor University will continue to work with families and young people to improve services and support**