



DementiaUK

Helping families face dementia

Age-appropriate support in care homes

Jules Knight - Consultant Admiral Nurse
for Young Onset Dementia, Dementia UK

Andy Dearden – family carer

Fran Mada - Admiral Nurse, Dementia
Oxfordshire a service provided by Age UK
Oxfordshire.

Rachel Beckett – Chairman
Wellburn Care Homes

www.dementiauk.org
info@dementiauk.org
@DementiaUK

Registered Charity Number 1039404

What is young onset dementia?



Dementia is considered young onset when the onset of symptoms starts before the age of 65

People living with rare dementia tend to be younger people.

Rare dementias affect
Between five and 15%
of people

Numbers of people living with young onset dementia

**70,800 around
7.5% of the total
number of people
living with
dementia**

Care homes / supported living



- We do not have figures for the number of people with young onset living in care homes or supported living accommodation
- Of the thousands of care homes listed for dementia on the CQC site, just over 30 list young onset as a specialism
- There is a severe shortage of appropriate alternatives to living at home
- Younger people with dementia are cared for at home for longer than those with late onset dementia, almost nine years compared to four years, resulting in severe strain on the family

(Bakker et al, NeedYD study 2014)

Oxfordshire

There are more than 5500+ people currently diagnosed with **dementia**

413

People living with young onset dementia



The impact of young onset dementia on a family



- Different stage of life
- Different impact
- Different issues
- Variation in services

Lived experience: results from research

- Lack of guidance or reference for families on choosing a care home
- Professionals not aware of different needs of younger people with dementia
- Non or sparse age-appropriate care homes nationally
- When available, very far from home
- Lacking age-appropriate specialism

Real life experiences

Alana visited four care homes and phoned more. "Several shocks along the way"

Ellen visited 50 care homes: "Many of those being specialist in dementia... only three said they would manage his needs and some of these were a long distance from home"

Real life experiences continued...

“A lot of places wouldn't take him. It was over 65s and not under, he was under 60”

“There just was not the facilities for a young person. Everything is geared, especially in our area, around or on the older people”

Thomas: “I know care homes for old people where will my wife go. We live separate, we are not divorced are we?”

Negative real life outcomes

	Hospital admission 1	Care home 1	Hospital readmission	Care home 2	Hospital readmission
Alana	X	X			
Ellen	X	X	X	X	
Mary	X	X			
Maxwell	X	X		X	X
Thomas	X	X	X	X	

Points raised: a homely care home

- Homes that meet needs including religion
 - Homes that respect that people are sexual beings. Privacy considered
 - Spaces for meaningful activities that are age considerate. Walking space, gyms, swimming pools
 - Home that allow children to visit and not be in bedroom spaces all the time. Ellen viewed all homes with her daughter around 18-19 years old
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**Young onset dementia:
choosing a care home**



**The transition into a
care home requires
a family-centred
approach**

Young Onset Dementia Admiral Nurse Service



Case study – Phil and Gemma

Transitioning to end of life

- Gemma is happily married to Phil, they have two adult children
- Phil was diagnosed with young onset Alzheimer's disease age 55, he is now 65 and has been resident in a care home for the past six years
- Gemma described Phil being in the late stages of dementia and felt that he was distressed. She stated "it's been very hard to witness this level of suffering"
- Gemma felt that the care home staff and GP were not listening to her, and she was informed that her husband's symptoms were "normal for dementia, especially for a younger person"



Admiral Nurse Support

- We looked at Phil's symptoms holistically, and we thought that he had pain that hadn't been recognised or treated appropriately
- We looked at how Phil could be supported and engaged physically and emotionally – Namaste Care
- Gemma's emotional and psychological needs were addressed; she expressed that she had never been "heard and supported before"
- Admiral Nurse researched local services, and advised Gemma to contact the local Palliative Care Team

Outcomes for Gemma and Phil

- Gemma expressed her appreciation of being “heard and supported” as she had felt isolated and alone and that “no one had really listened” to her
- The Palliative Care Team is now working to coordinate Phil’s care, and Gemma can contact them if she has any concerns, and they will come and review
- Phil is now much more settled and relaxed with only brief periods of distress, and Gemma feels very relieved
- Gemma no longer feels isolated and alone as a carer, she understands that she can contact the Admiral Nurse Helpline again for support for her and for Phil
- Gemma now has bereavement support from a psychologist working within the Palliative Care Team

Outcomes for the care home

- Gemma educated the care home staff working with Phil on pain and dementia
- Gemma used her new knowledge of Namaste Care and shared this with the care home staff
- The care home developed good connections with the Palliative Care Team
- Hopefully, going forwards the care home will recognise distressed behaviours, and appreciate that there are strategies for managing them



**At the forefront of
young onset dementia
care in the region.**

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The Manor.



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**How
The Manor
was born.**

The Manor.

How The Manor was born.

- St Catherine's home in York was transformed into a dedicated dementia care home.
- During the R&D phase, one conversation about young onset dementia started Wellburn on the path to The Manor.
- Just how little dedicated support, care and awareness there was for those living with young onset dementia was clear.

The Manor.



How The Manor was developed.

- We stepped out of our comfort zone and entered completely uncharted territory.
- We had no reference point for The Manor with next to no competitor analysis available.
- We were aware of the risks, but driven by the urgent need for a dedicated home

The Manor.

The whole project was driven by a burning desire to provide the region with its first ever home dedicated to those living with young onset dementia.

The Manor would provide a home that offered support, understanding and age-appropriate care.



The Manor.



**What are the
challenges
we've faced.**

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The Manor.

Challenges we've faced.

- Reaching those who need The Manor.
- Raising awareness of young onset dementia.
- Forging new relationships with charities, social teams and other key players in the care sector.
- Amplifying the voices of those living with a diagnosis who are often not being heard.

The Manor.



Ongoing challenges we face.

- As the only dedicated young onset dementia home in the region, we not only need to raise awareness that we're here, but awareness of young onset dementia in general.
- The catchment area we serve is huge, which brings its own unique challenges.

TheManor.

**We know from the numbers,
that the urgent need for
dedicated age-appropriate
care is there.**

**But for us to provide it, the
single biggest problem we
face is reaching those people
to let them know we're there.**



The Manor.



Overcoming challenges.

- Encouraging and facilitating conversations with key professionals across the spectrum.
- Creating a clear message and regular communication tools, such as stand-alone website, newsletter sign -ups etc.
- Young onset dementia awareness campaign

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Our brand new awareness campaign is not just a sales tool.

Our hope is that it can act as a catalyst to spark conversation, awareness, and understanding, helping to inspire empathy and encourage action.



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Awareness campaign.

Our new campaign video highlights the impact young onset dementia can have on family and friends. Our campaign aims to raise awareness, understanding and to reach those who need help the most, and to let them know that there's someone that understands what they're going through and that we're there for them every step of the way.

The Manor.



For more info and to sign up for our newsletter, visit:
dementia-wellburncare.co.uk

Follow our campaign at:
[@dementia_wellburncare](https://twitter.com/dementia_wellburncare)




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Watch our video.

Every like, share and comment, is a step closer to reaching those who are desperate for help, support and understanding.

The Manor.

**Any
questions?**

