Trinity College Dublin
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# Best Practice Guidelines for Radiography & Radiation Therapy

IIRRT Study Day on Dementia

20th January 2022

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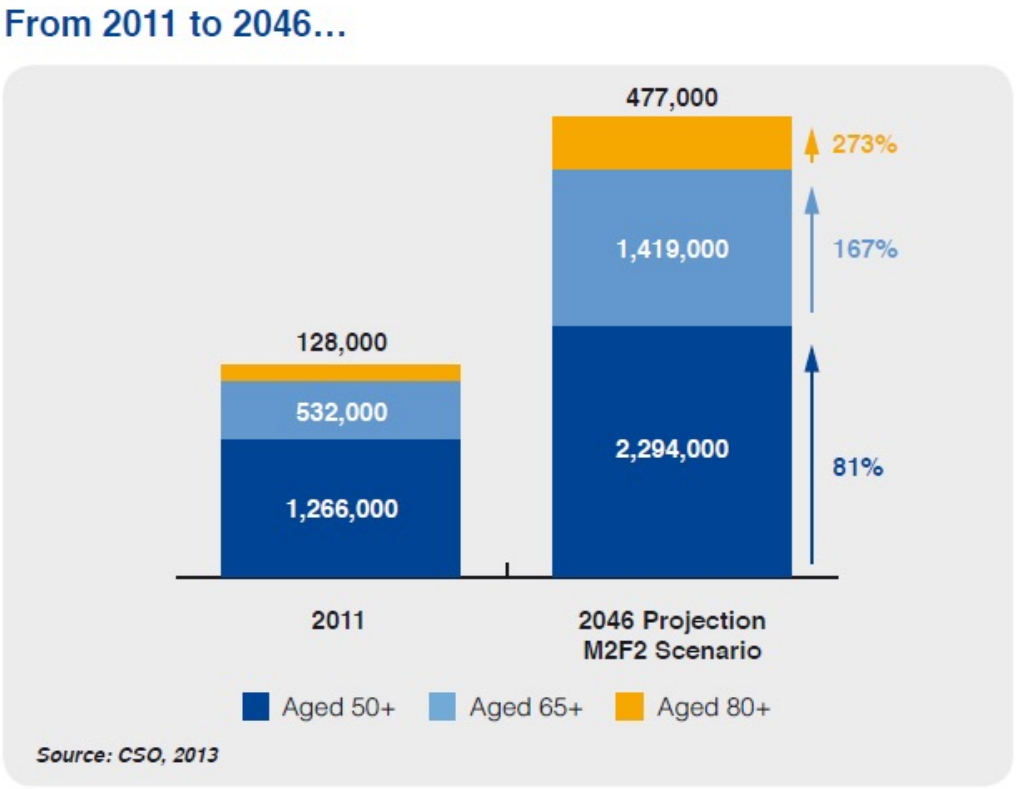
# Overview

- Relevance to radiography/radiation therapy
- Policy and guidelines
- Studies to date radiography and RT
- Meaningful changes we can make in clinical practice
- Additional staff resources
- Over to you – what changes can you make in your clinical practice?

# Relevance to Radiography/Radiation Therapy




- Those aged ≥50 will increase from 27.7% (1.3 million) of the total population to nearly 41% (2.3 million) by **2046**
- The number of those aged ≥65 is projected to increase significantly from 531,600 to 1.42 million (or by 167%)
- Those aged ≥80 is expected to nearly **quadruple**, increasing from 128,000 to 476,700

Source: DoH HaPAI Research Team. Healthy and Positive Ageing for All: Research Strategy 2015-2019

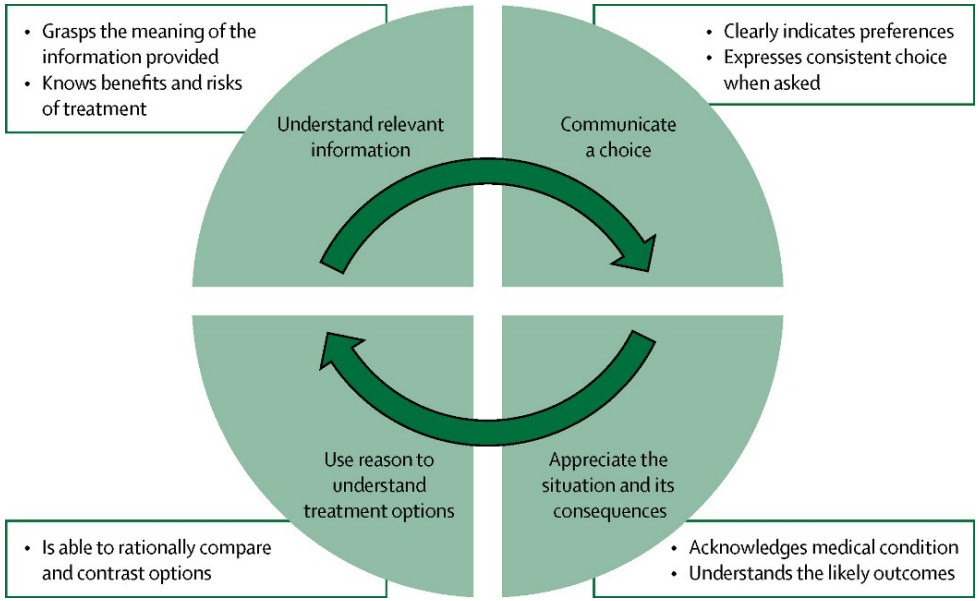
# Relevance to Radiography/Radiation Therapy

- RT: Predominantly treating an older patient population, in which the prevalence of dementia increases exponentially after the age of 65
- Diagnostic: Patients with dementia are often referred for a variety of imaging modalities for diagnosis and injuries
- Provision of care can be challenging
- BPSD are often challenging manifestations in radiography/radiation therapy
- Traditionally, HCPs receive little education on dementia care
- Previous studies have suggested negative attitudes were held towards persons with dementia

Kada S. Radiographers' attitudes towards persons with dementia. European Journal of Radiography. 2009 Dec 1;1(4):163-8.

# Relevance to Radiography/Radiation Therapy

- Informed consent (capacity)
- Ability to understand procedural/treatment requirements
- Duty to maximise capacity




Soto-Perez-de-Celis, E., et al. (2018). "Functional versus chronological age: geriatric assessments to guide decision making in older patients with cancer." The Lancet Oncology **19**(6): e305-e316.

# Person-Centred Care

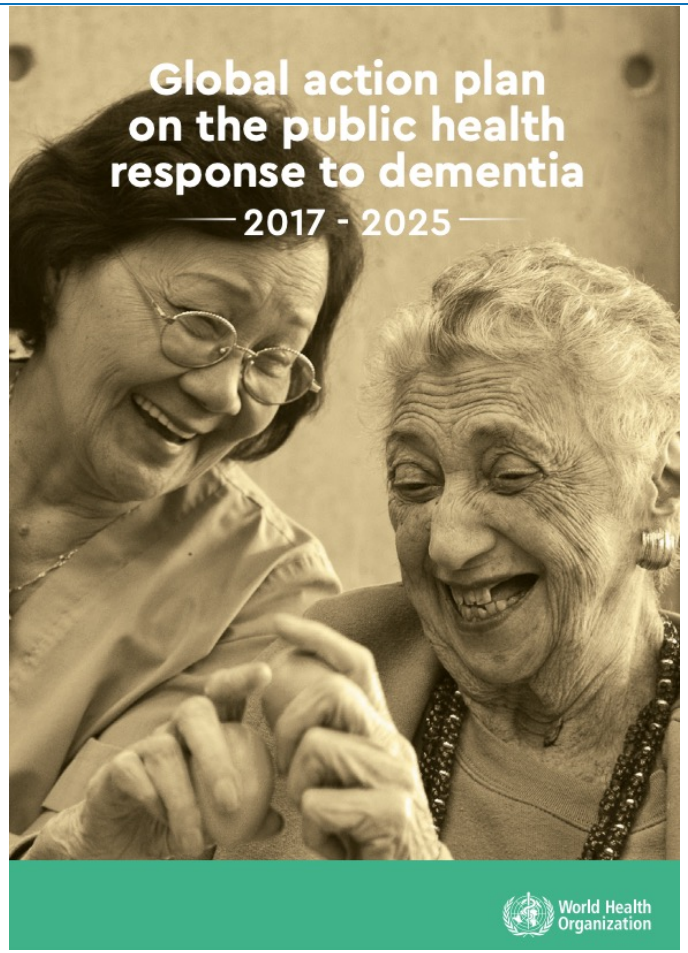
"Person-centred care entails putting patients at the centre of all care and treatment through collaborative working and fostering their active participation in decision-making.

In the context of caring for people with dementia, the concept particularly emphasises **the importance of not losing sight of the person and avoiding dehumanising actions and behaviours**"

Society and College of Radiographers (2015)

# WHO

## Global Dementia Policy

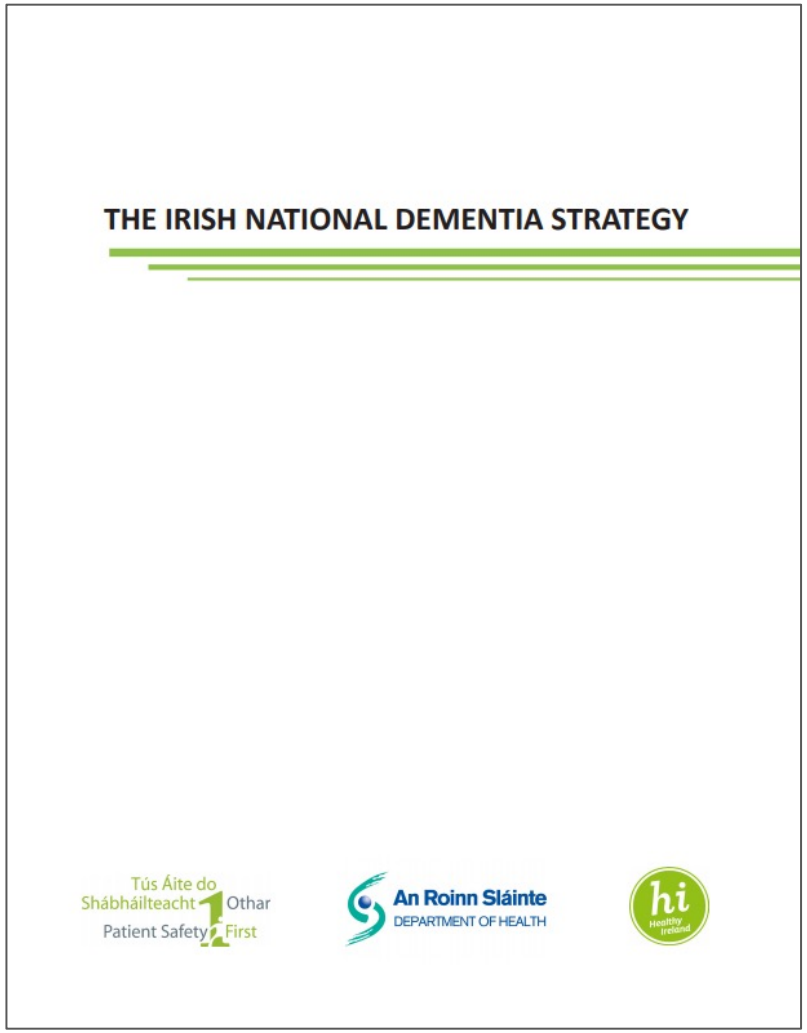



1. Dementia as a public health priority
2. Dementia awareness and friendliness
3. Dementia risk reduction
4. Dementia diagnosis, treatment, care and support
5. Support for carers
6. Information systems
7. Dementia research and innovation

Hopkinson JB, Milton R, King A, Edwards D. People with dementia: what is known about their experience of cancer treatment and cancer treatment outcomes? A systematic review. Psycho-Oncology. 2016 Oct;25(10):1137-46.

# Guidelines

National Dementia Strategy



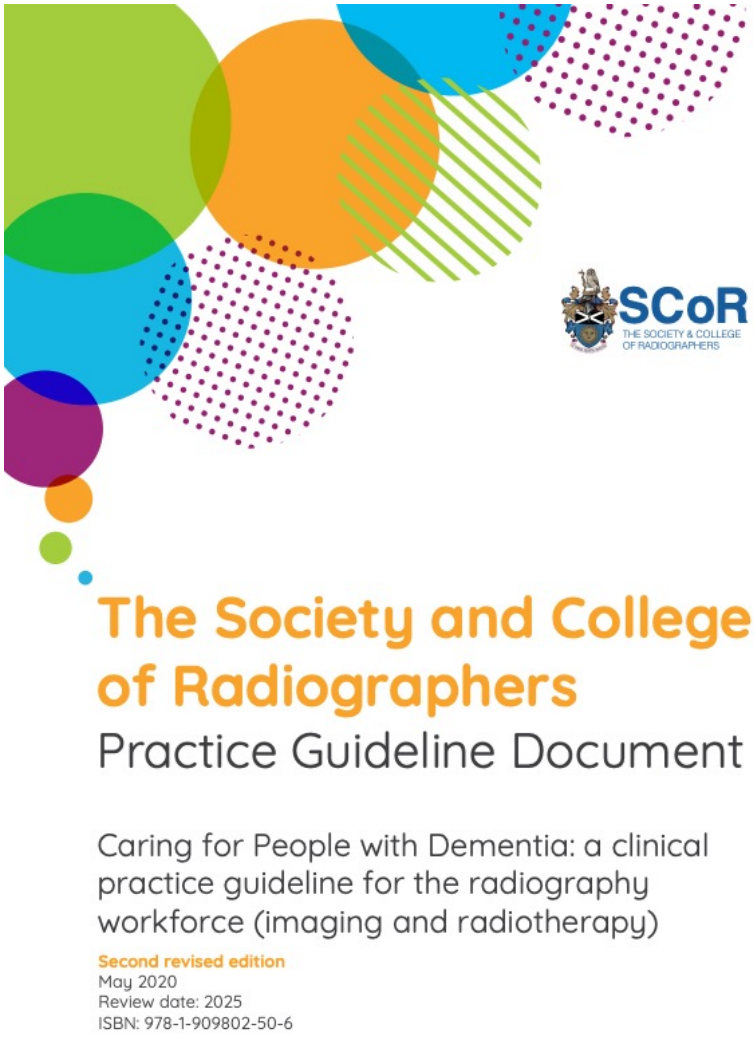

Key Principles:

1. Integrated care approach is recommended
2. Services should be tailored to the needs of those with dementia
3. All communications should be as accessible as possible
4. **All those dealing with people with dementia should receive appropriate training**



https://assets.gov.ie/10870/3276adf5273f4a9aa67e7f3a970d9cb1.pdf

# Guidelines: Caring for Patients with Dementia and Cancer

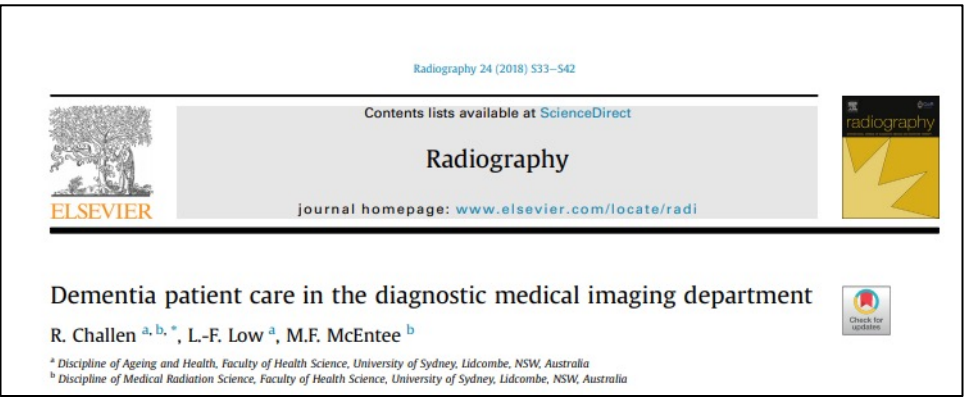



- Communication
- Deficiencies in person-centred care
- Need for role-specific, tailored training (clinical and non-clinical staff)
- Dementia-friendly environment
- Time and resource pressures
- Optimisation of patient and carer experience
- Identification of people with dementia

https://www.sor.org/getmedia/db2b70ad-2771-42f1-a204-009fde177071/sor_dementia_academic_doc_llv2.pdf

# Studies to Date…..

Radiography



Radiography 24 (2018) S33–S42

Contents lists available at ScienceDirect

Radiography

journal homepage: www.elsevier.com/locate/radi

Dementia patient care in the diagnostic medical imaging department

R. Challen [a, b, *], L.-F. Low [a], M.F. McEntee [b]

[a] Discipline of Ageing and Health, Faculty of Health Science, University of Sydney, Lidcombe, NSW, Australia
[b] Discipline of Medical Radiation Science, Faculty of Health Science, University of Sydney, Lidcombe, NSW, Australia

Included:

- People with dementia (n=4)
- Carers (n=6)
- Student radiographers (n=19)
- Radiographers (n=8)

Interviews

Focus groups

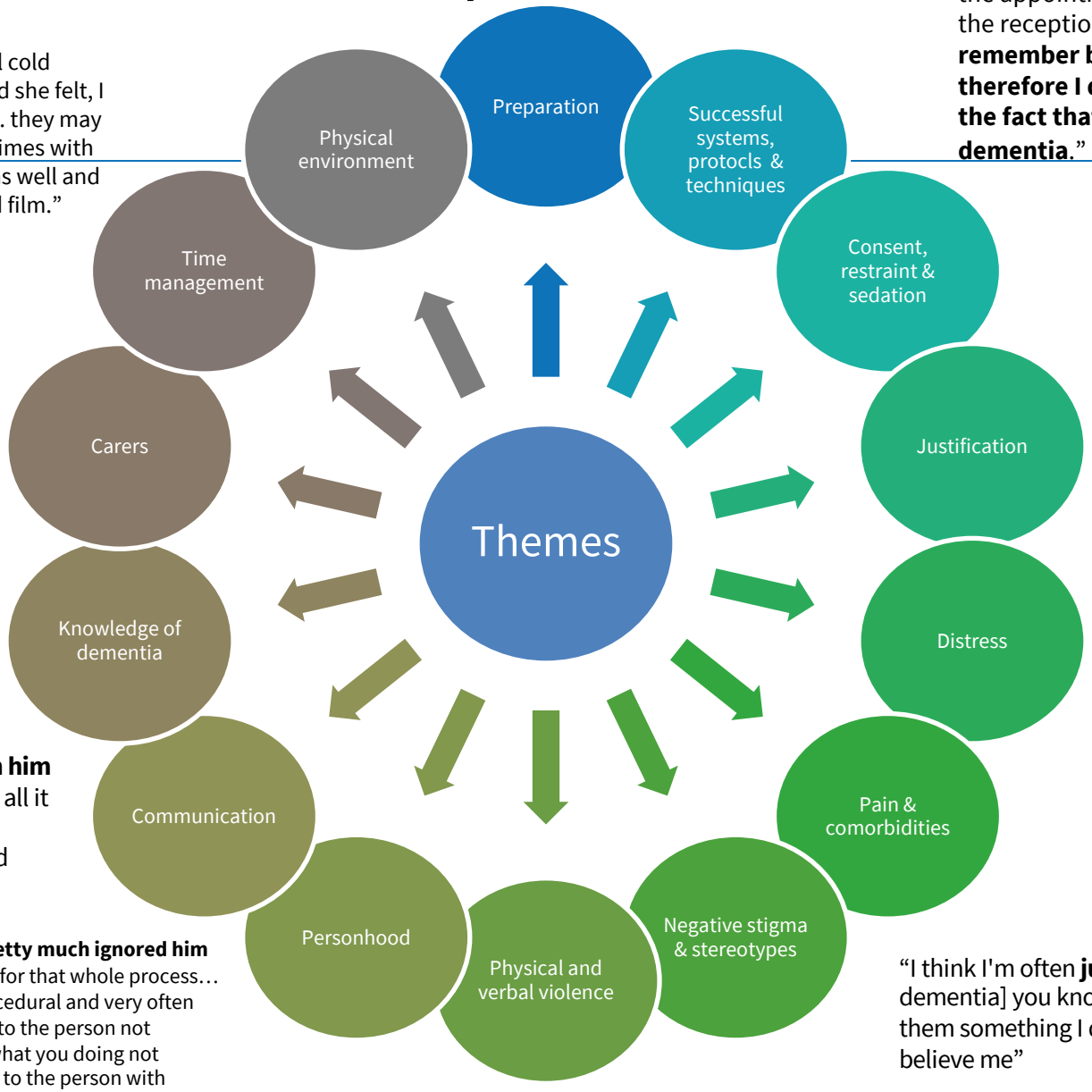
| People with dementia and carers | Radiographers and students |
|---|---|
| 1. What was your experience having a scan in the radiography department?<br>2. Did the radiographers take dementia into account when taking the scan?<br>3. What things worked really well?<br>4. What would you like to happen differently next time you have a scan?<br>5. What do you think radiographers should know about dementia? | 1. What do you think dementia is?<br>2. Does someone want to share an experience they have had scanning a person with dementia?<br>3. What did you learn from this experience?<br>4. If you were aware your next patient had dementia, how would approach that encounter?<br>5. What do you think about the role of the carer in these situations?<br>6. What protocols or guidelines have you come across in practice?<br>7. How do you think curricula and training in radiography could be improved to benefit people with dementia? |

Challen R, Low LF, McEntee MF. Dementia patient care in the diagnostic medical imaging department. Radiography. 2018 Oct 1;24:S33-42.

# Common Issues: Patients/Carers

"My mum was … a real cold freak, she couldn't, and she felt, I mean really felt cold … they may well shake, and sometimes with dementia they shake as well and you want to get a good film." (carer)

"I would like to see at the time the appointment is made with the receptionist… **I can't remember being asked and therefore I didn't volunteer the fact that Mary had dementia**."




"In the case of a mammogram she probably shouldn't even have bothered having it done in retrospect, there was really no need."

"I was required to wait outside and no amount of discussion on my part was going to change their minds about that, they were adamant and very much taken to the opinion of the experts so there was **no real partnership** in care which I think was sad." (carer)

"They caused him a great deal of distress and pain that perhaps could've been minimised or avoided altogether … **if they involved John with the process and strategy** and I said to them I'm not usually rude but I said to them it's not that he is non-compliant and I don't think that's an appropriate thing to be putting in the notes, I said it's he is in severe pain and **had you allowed me to help** you perhaps there would've been a better outcome for him and for you. I was just very angry."

"They **didn't communicate with him** directly very well at all it was like he wasn't someone who could communicate…"

"They've **pretty much ignored him as a person** for that whole process… it's very procedural and very often not relating to the person not explaining what you doing not explaining it to the person with dementia." (carer)

"I think I'm often **judged** [about dementia] you know when I tell them something I don't think they believe me"

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Challen R, Low LF, McEntee MF. Dementia patient care in the diagnostic medical imaging department. Radiography. 2018 Oct 1;24:S33-42.

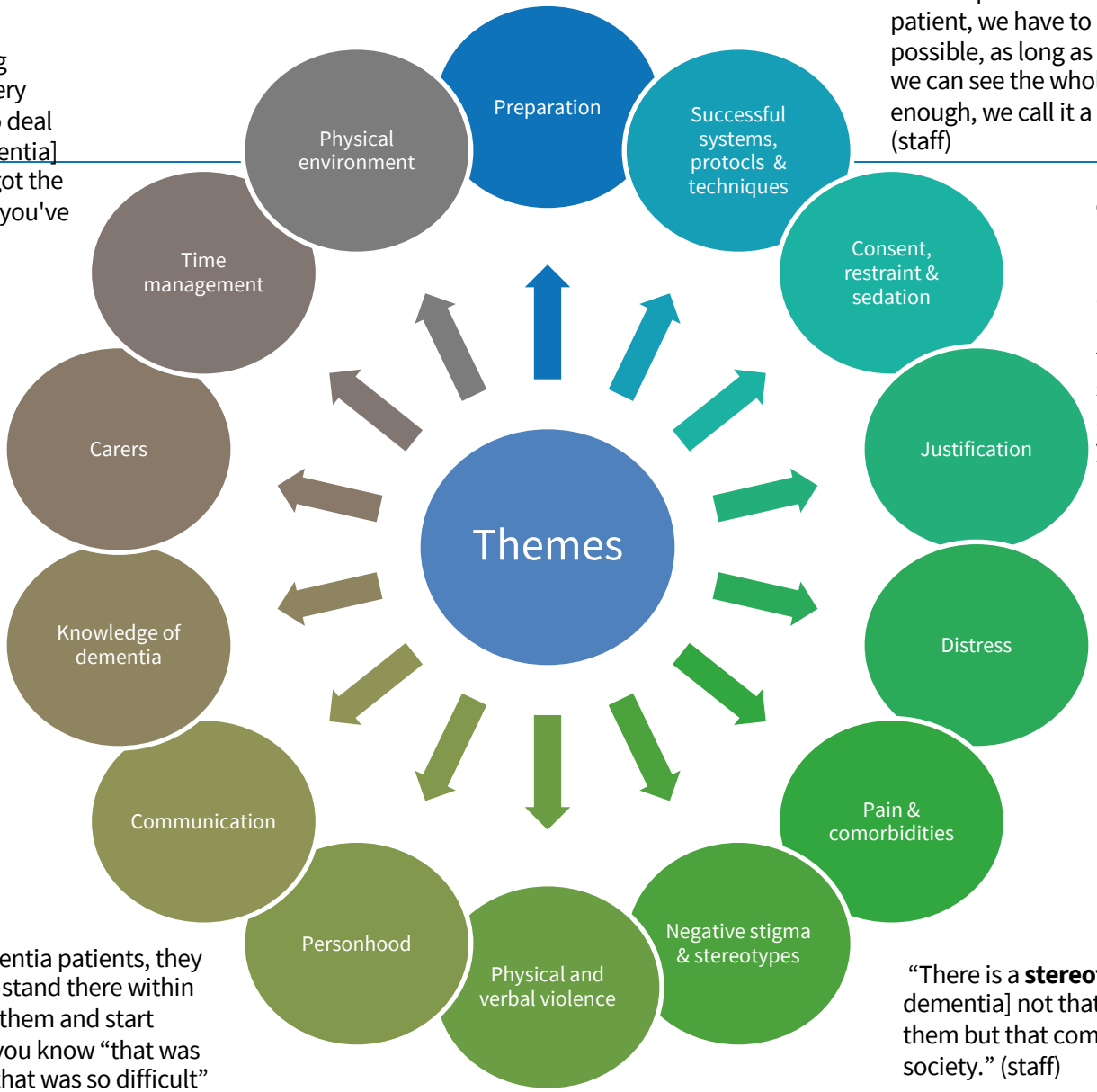
# Common Issues: Students/Staff

"As radiographers doing radiography there is a very small amount of **time** to deal with patients [with dementia] and quite often you've got the time pressures because you've got other people sitting outside so it gets very complicated." (staff)

"I have just found that they seem to be **comforted by somebody that does know them**." (student)

"I think what was most surprising was the fact that medical staff, certainly the referring doctor, **he had no idea about dementia at all**." (staff)

"With dementia patients, they would just stand there within earshot of them and start saying oh you know "that was so hard" "that was so difficult"




"If they need a chest x-ray we do not need to position them like a normal patient, we have to do it as simply as possible, as long as in the projection we can see the whole lungs that is enough, we call it a modified view." (staff)

"So it poses a **real ethical concern** to the radiographers about how much you **restrain** if they are not already restrained in the bed, you want them to be comfortable and secure and not to come to any harm, or how much do you remove those restraints in order to image them to a point that is necessary?

"One was really really scared and terrified and she thought they were trying to kill her with the x-rays and you know they were taking her in to kill her." (student)

"There is a **stereotype** [about dementia] not that you teach them but that comes from society." (staff)


Challen R, Low LF, McEntee MF. Dementia patient care in the diagnostic medical imaging department. Radiography. 2018 Oct 1;24:S33-42.

# Experience in Cancer Care

Patients and HCPs

**Table 2** Thematic framework of findings

| Theme | Subtheme |
|---|---|
| (1) Leading up to the initial cancer consultation | (1.1) Transition to tertiary care<br>(1.2) Preparation for the first oncology consultation |
| (2) Communicating clinically relevant information | (2.1) Taking more time<br>(2.2) Navigating treatment decision-making information<br>(2.3) Dementia-specific cancer treatment considerations<br>(2.4) Decision-making agency |
| (3) Adjustments to cancer care | (3.1) Continuity of care<br>(3.2) Proxy healthcare professionals |
| (4) After cancer treatment finishes | (4.1) Ongoing decision-making processes<br>(4.2) Lasting impact of treatment decisions |

- Some baseline information on level of functioning and understanding deemed useful for HCPs
- More time needed for appointments
- Dementia-oriented information needed and support with decision making
- Continuity of staff and familiarity N.B.
- Community based care in the aftermath of treatment recommended

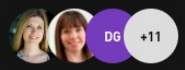
McWilliams L, Farrell C, Keady J, *et al.* Cancer-related information needs and treatment decision-making experiences of people with dementia in England: a multiple perspective qualitative study. *BMJ Open* 2018;**8:**e020250. doi: 10.1136/bmjopen-2017-020250

# Experience in Cancer Care

Centre for Dementia Research

## CANCER AND DEMENTIA IN HOSPITALS RESEARCH (CANDEM)

Cancer and dementia are both common conditions in older people. In the UK half of all people with cancer are aged over 75 and there are currently 850,00 people living with dementia.



**Aim**

To identify the size, characteristics, cancer treatment and care needs of people living with cancer and dementia in the UK

https://www.leedsbeckett.ac.uk/research/centre-for-dementia-research/candem-study/

# Experience in Cancer Care

## Results from the CANDEM Study

| Main theme | Sub themes |
|---|---|
| **Reliance on family support** – to access cancer treatment and care | **Practical support** – was required to attend appointments, manage symptoms and 'fill the gaps' that could occur as a result of memory loss<br>**Emotional support** – including reassurance was provided during treatment and attendance at hospital appointments<br>**Obligation and expectation to support** – families felt an obligation to provide the required support, sometimes even if they were a distant relative |
| **Ability of family to support** – families had varied abilities and resources to provide support needed | **Extent of family network** – some family networks were small with support falling to a small number of members who could feel alone<br>**Physical ability to provide support** – some relatives, particularly spouses, may also have health problems or physical and/or cognitive frailty which limited their ability to provide practical support<br>**Willingness to accept help** – some people with CCD were not welcoming of the support relatives wished and needed to provide<br>**Knowledge of the person and their wishes** – in some cases families were unsure what the person with cancer or dementia would want with regard to treatment, when they were unable to express this for themselves<br>**Harmony or conflict among family members** – while in some cases families came together to provide support, in others there was conflict around treatment and care decision-making |
| **The impact of providing support** – providing support had a range of usually negative impacts on families | **Guilt, stress and worry** – families often felt guilt, stress and worry, particularly when they had a central role to play in decision-making around cancer treatment and care and when facing extended periods of hospital attendance for treatments. Some families felt alone and unsupported at times. |
| **What if there is no family network?** – not everyone had a family network they could call upon to provide support. | **Who fills the gaps?** - When there was no family network it was unclear whose responsibility it was to fill the gaps.<br>**Bouncing or assuming responsibility** – This often led to the person being 'bounced around' the system as different health and social care services argued about whose responsibility this was and who would pay for any required support |

*CCD = comorbid cancer and dementia

Surr CA, Kelley R, Griffiths AW, Ashley L, Cowdell F, Henry A, Collinson M, Mason E, Farrin AJ. Enabling people with dementia to access and receive cancer treatment and care: the crucial role of supportive networks. Journal of geriatric oncology. 2020 Sep 1;11(7):1125-31.

# What Can We Do Better?

## Results from the CANDEM Study

Recommendations and potential strategies and interventions for oncology hospital departments and staff to improve cancer care and treatment for people with dementia and their families

| Recommendations | Suggestions for implementation |
|---|---|
| **Improved dementia awareness, identification and documentation** | |
| 1. Ask about memory problems at an initial appointment (and periodic follow-ups) | . Add a question about possible memory problems to existing assessment and review forms |
| | . Include a follow-up question(s) about the functional impact of any memory problems, especially as relates to undergoing cancer treatments |
| 2. Record dementia and associated needs accessibly in oncology medical records | . Create designated space in the electronic medical record to record dementia (or note memory problems) and related needs and support in place |
| | . Tag electronic medical-records with a flag/icon/pop-up which alerts staff accessing the record that the patient has dementia (or memory problems) |
| **Providing staff with training and tools to support person-centred dementia care** | |
| 3. Ensure oncology staff has access to practical information and training on dementia | . Collate information in a shared drive, e.g. details of local referral pathways for memory assessment and support, relevant clinical guidance [28] |
| | . Promote staff access to high-quality dementia training tailored to their role (e.g. Macmillan dementia training especially for oncology staff) to increase staff knowledge and confidence, and reduce the potential for dementia stigma |
| 4. Use simple tools to support discussion of dementia and related needs | . For example, the simple 'This is Me' leaflet from Alzheimer's Society can facilitate collection of personal information key to caring well for someone with dementia |
| **Support for people to attend hospital for cancer treatment and care** | |
| 5. Offer flexibility in timing and location of appointments where possible | . Conduct some appointments by telephone (e.g. follow-ups) |
| | . Schedule as best suits the person with dementia (e.g. always afternoon slots) |
| | . Longer slots for key consultations and some treatment sessions (e.g. radiotherapy) |
| 6. Give consistency of people and place where possible | . Provide the same clinician(s) and treatment seat/room where possible |
| 7. Mitigate hospital travel challenges | . Ensure people with dementia are asked about requirements for an escort seat on patient transport at the time of booking |
| | . Broaden support at hospital entrances (e.g. volunteer staff) to explicitly include waiting with people with dementia while their carer parks/fetches the car |

Laura Ashley, Rachael Kelley, Alys Griffiths, Fiona Cowdell, Ann Henry, Hayley Inman, June Hennell, Margaret Ogden, Maria Walsh, Liz Jones, Ellen Mason, Michelle Collinson, Amanda Farrin, Claire Surr, Understanding and identifying ways to improve hospital-based cancer care and treatment for people with dementia: an ethnographic study, *Age and Ageing*, Volume 50, Issue 1, January 2021, Pages 233–241, https://doi.org/10.1093/ageing/afaa210

# This is me®

This leaflet will help you support me in an unfamiliar place.

**My full name is**



**Please attach a favourite photo of yourself here.**

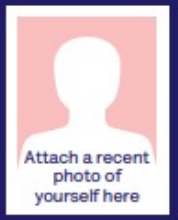
You can also attach a recent photo of yourself on the next page.

- See the notes on page 4 to help you complete **This is me**, including examples of the kind of information to include.
- Keep this leaflet with you and put it in a suitable place so that all the people caring for you can see and refer to it easily.

In partnership with

Royal College of Nursing

Alzheimer's Society
United Against Dementia




A person who has dementia, delirium or other communication difficulties can find changes, like moving to an unfamiliar place or meeting new people who contribute to their care, unsettling or distressing. **This is me** can help to reduce this distress. It helps health and social care professionals build a better understanding of who the person really is, which can help them deliver care that is tailored to the person's needs.

**This is me** should be completed as early as possible, so the person can take it to a new place or give it to new people who contribute to their care. It should be updated as necessary.

**This is me** should be filled in by the individual(s) who know the person best and, wherever possible, with the person involved. It is not a medical document.

## About me

(See the notes on page 4 for ideas about the kind of information to include)

Name I like to be called

Where I live (area not the full address)

The carers/people who know me best

I would like you to know

My personal history, family and friends, pets and any treasured possessions

## My background

(See the notes on page 4 for ideas about the kind of information to include)

My cultural, religious and spiritual background

My interests, jobs and achievements

Favourite places I have lived and visited





https://www.alzheimers.org.uk/sites/default/files/2019-03/Alzheimers-Society_NEW_This-is-me-booklet_190318.pdf

## My habits and routines

(See the notes on page 4 for ideas about the kind of information to include)

The following routines are important to me

Things I like to do for myself

Things I might want help with

Things that may worry or upset me

What makes me feel better if I am anxious or upset

## My communication and mobility

(See the notes on page 4 for ideas about the kind of information to include)

My hearing and eyesight

How we can communicate

My mobility



## My personal habits

(See the notes on page 4 for ideas about the kind of information to include)

Things that help me sleep

My personal care

How I take my medication

My eating and drinking

## Other

(See the notes on page 4 for ideas about the kind of information to include)

Other notes about me

Date completed

Completed by

Relationship to the person

☐ I am happy for the information I have provided to be used by health and social care professionals to provide care and support. If they wish to use it for a different purpose, they must ask first.





https://www.alzheimers.org.uk/sites/default/files/2019-03/Alzheimers-Society_NEW_This-is-me-booklet_190318.pdf

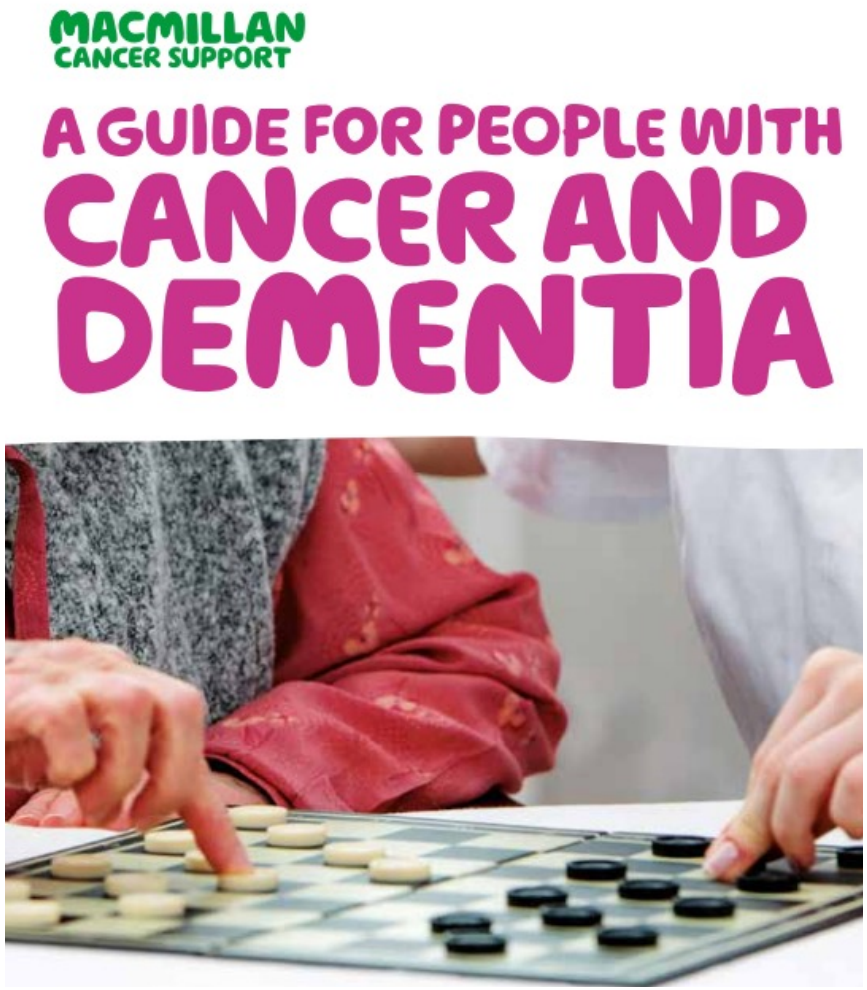
# What Can We Do Better?

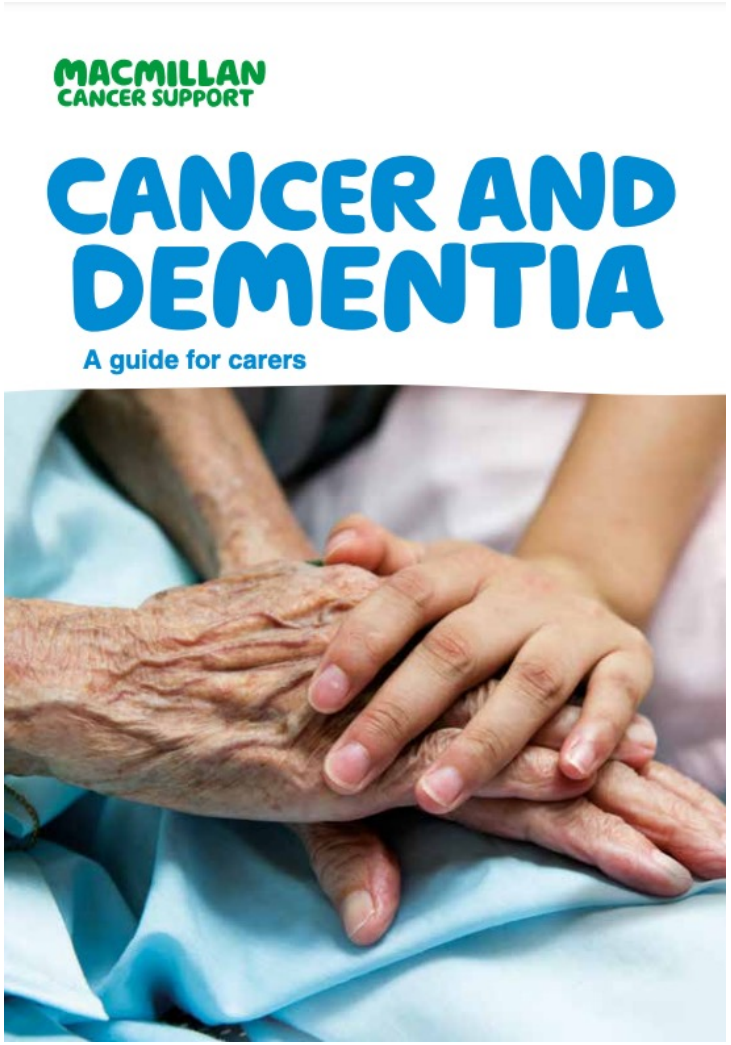
## Results from the CANDEM Study

| | |
|---|---|
| **Providing a supportive physical environment** | |
| 8. Enhance oncology departments to be more dementia friendly | . Draw on existing guidance for hospitals [29], e.g. clearer signs for toilets and exits, clocks and calendars on walls, colour coding to distinguish areas |
| | . Have dementia-friendly books and activities (memory boxes) in waiting areas |
| 9. Make the environment familiar before treatment starts | . Provide leaflets with colour photos (or YouTube video) of the departments and equipment |
| | . Offer pretreatment visits (e.g. some radiotherapy departments run regular information sessions for new patients, which include a tour and demo of the equipment) |
| **Supporting treatment decision-making** | |
| 10. Provide accessible written summaries of key information and discussions | . Give short simple bullet points |
| | . Use any idiosyncratic terms used by the person with dementia (e.g. Big Machine) |
| | . Include visuals to explain things (e.g. have paper in consulting rooms preprinted with a body outline for drawing information about tumour size and location) |
| 11. Enable easy communication with other key professionals | . Geriatricians in the Trust, for example, invite them to relevant department meetings, establish a communication pathway for seeking their input into care decisions |
| **Inclusion and support of families (where desired by patients and carers)** | |
| 12. Include carers in provision and discussion of care information | . Send a nominated family member copies of hospital letters |
| | . Incorporate the views of family when discussing treatment and care options |
| 13. Permit carers to be present during treatment | . Radiotherapy, for example, allow carers to help settle patients on the table, and then to use the tannoy/intercom to help instruct and reassure during treatment |
| 14. Recognise and ease the emotional and physical burden upon carers | . Ask carers how they are coping and consider their needs (e.g. getting time off work, own health problems) in care planning and support provision |
| | . Help carers with managing treatment side-effects (e.g. catheters, pain) by giving ample practical information and arranging needed support (e.g. district nurses) |
| | . Signpost carers to dementia and comorbid cancer-specific support resources, e.g. |
| | Macmillan's 'Cancer and Dementia: a Guide for Carers' booklet |
| | Alzheimer's Society's cancer section of their carers online support forum [30] |

Laura Ashley, Rachael Kelley, Alys Griffiths, Fiona Cowdell, Ann Henry, Hayley Inman, June Hennell, Margaret Ogden, Maria Walsh, Liz Jones, Ellen Mason, Michelle Collinson, Amanda Farrin, Claire Surr, Understanding and identifying ways to improve hospital-based cancer care and treatment for people with dementia: an ethnographic study, *Age and Ageing*, Volume 50, Issue 1, January 2021, Pages 233–241, https://doi.org/10.1093/ageing/afaa210

# Patient Information Resources






https://be.macmillan.org.uk/be/Funnelback/search.aspx?query=dementia

# Service Changes

Implemented by centres as a result of the CANDEM study

- More education and awareness – dementia training
- Environmental audits
- Better records of patients presenting with dementia
- Tailored information resources for patients and their carers
- Volunteers to assist with patients' arrival at the centre for their appointments (meet and greet)
- Appointment of dementia champions

# Dementia Champions

NHS
Royal Surrey
NHS Foundation Trust

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Home > Our services > Find a service > Dementia care > Dementia champions

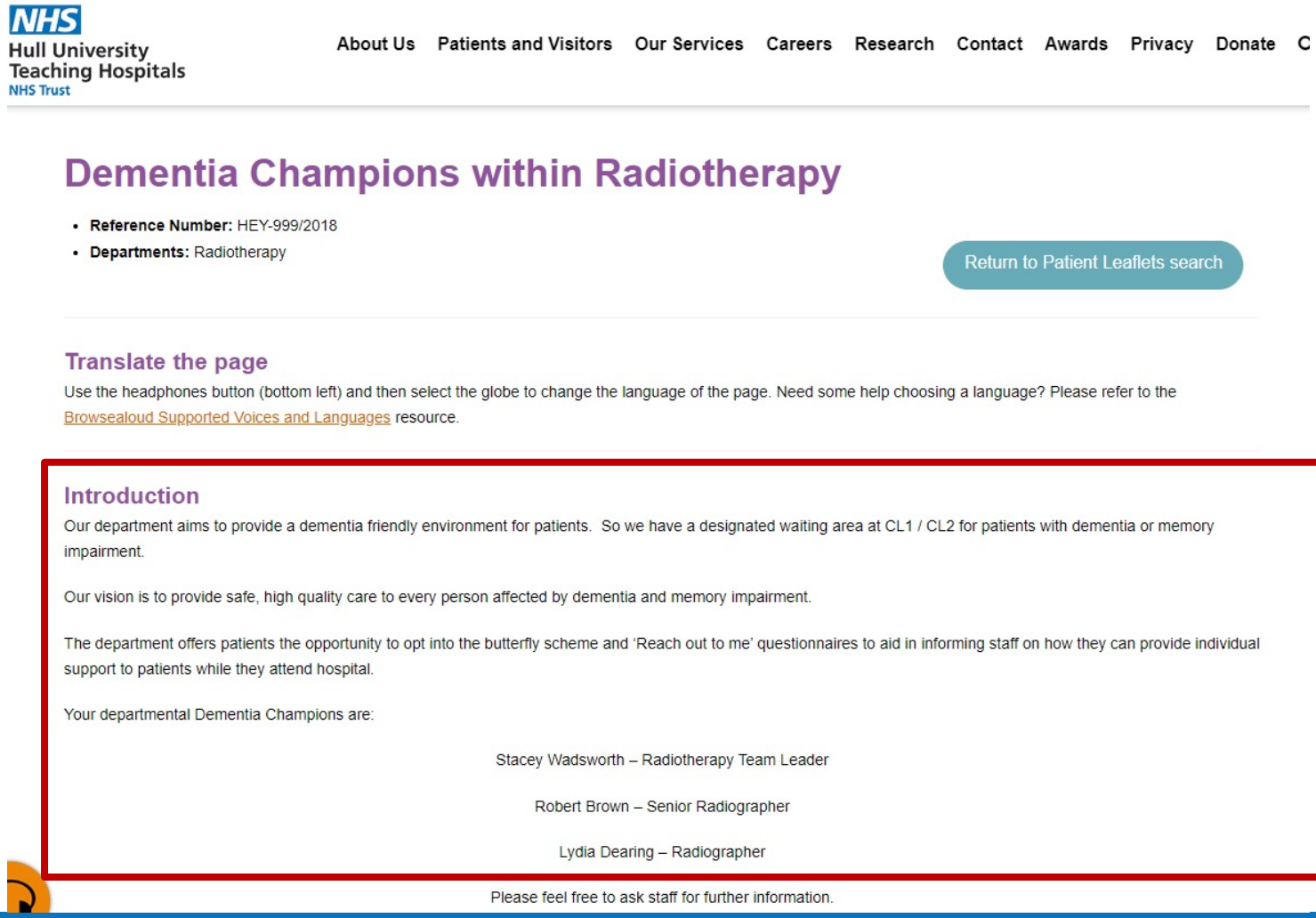
- Find a service
- Audiology
- Cardiology
- Clinical Immunology and Allergy
- Dementia care
- Memory boxes
- Activity volunteers
- Dementia friendly environments
- Caring for and supporting carers
- Dementia champions

## Dementia

## Dementia Champions

Every ward and department across the hospital has a member of staff who is an allocated dementia champion. Dementia champions are staff members that have a special interest in dementia and improving the care and experience of dementia patients in the area where they work. The dementia champions have / are encouraged to attend the Tier 2 training and attend the dementia champion meetings / teaching on a regular basis. The dementia champions working on the wards / departments are a good source of advice and support.

# Dementia Champions



NHS
Hull University Teaching Hospitals
NHS Trust

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## Dementia Champions within Radiotherapy

- **Reference Number:** HEY-999/2018
- **Departments:** Radiotherapy

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### Translate the page

Use the headphones button (bottom left) and then select the globe to change the language of the page. Need some help choosing a language? Please refer to the Browsealoud Supported Voices and Languages resource.

### Introduction

Our department aims to provide a dementia friendly environment for patients. So we have a designated waiting area at CL1 / CL2 for patients with dementia or memory impairment.

Our vision is to provide safe, high quality care to every person affected by dementia and memory impairment.

The department offers patients the opportunity to opt into the butterfly scheme and 'Reach out to me' questionnaires to aid in informing staff on how they can provide individual support to patients while they attend hospital.

Your departmental Dementia Champions are:

Stacey Wadsworth – Radiotherapy Team Leader

Robert Brown – Senior Radiographer

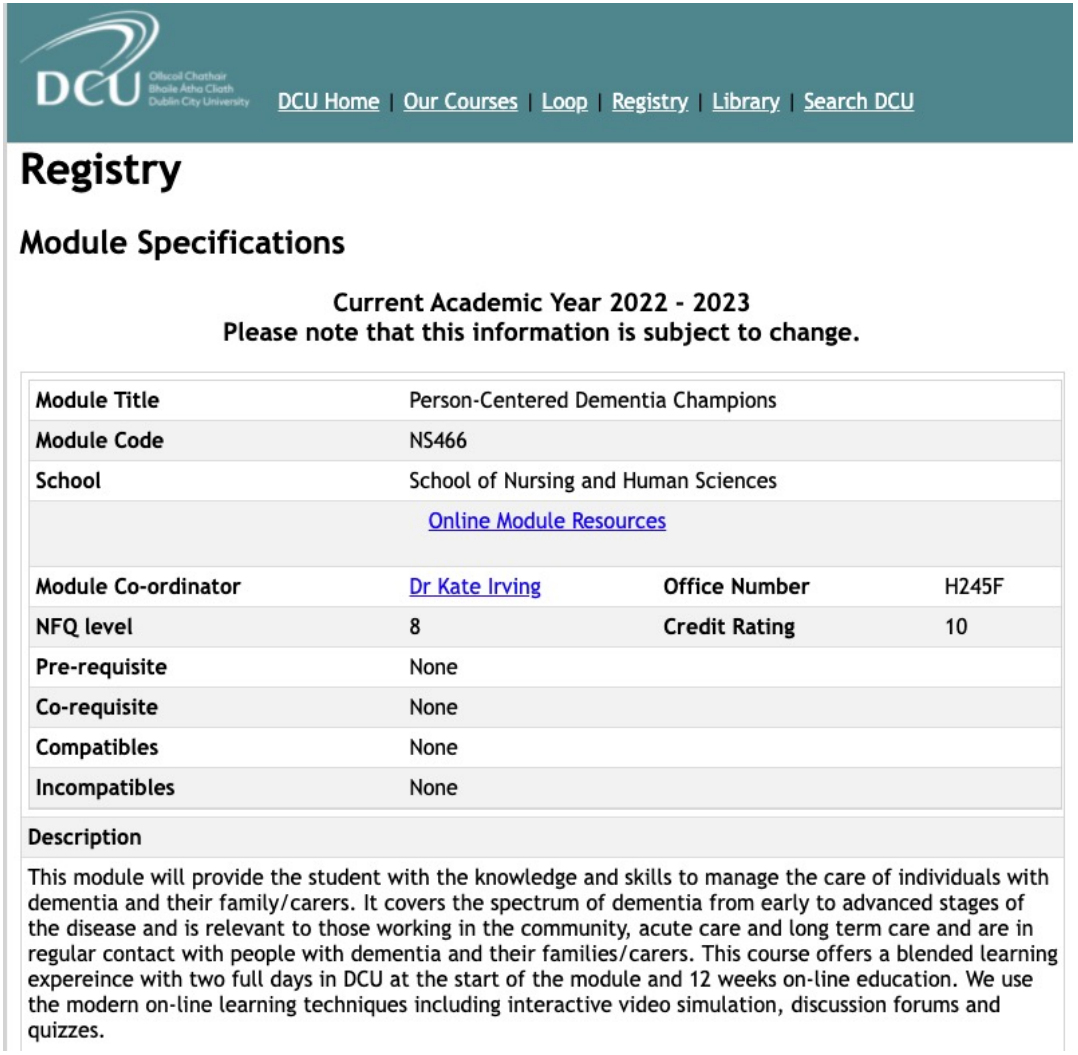
Lydia Dearing – Radiographer

Please feel free to ask staff for further information.



https://www.hey.nhs.uk/patient-leaflet/dementia-champions-within-radiotherapy/

# Dementia Champions Course



DCU Ollscoil Chathair Bhaile Átha Cliath Dublin City University

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## Registry

### Module Specifications

**Current Academic Year 2022 - 2023**
**Please note that this information is subject to change.**

| | | | |
|---|---|---|---|
| **Module Title** | Person-Centered Dementia Champions | | |
| **Module Code** | NS466 | | |
| **School** | School of Nursing and Human Sciences | | |
| | Online Module Resources | | |
| **Module Co-ordinator** | Dr Kate Irving | **Office Number** | H245F |
| **NFQ level** | 8 | **Credit Rating** | 10 |
| **Pre-requisite** | None | | |
| **Co-requisite** | None | | |
| **Compatibles** | None | | |
| **Incompatibles** | None | | |

**Description**

This module will provide the student with the knowledge and skills to manage the care of individuals with dementia and their family/carers. It covers the spectrum of dementia from early to advanced stages of the disease and is relevant to those working in the community, acute care and long term care and are in regular contact with people with dementia and their families/carers. This course offers a blended learning expereince with two full days in DCU at the start of the module and 12 weeks on-line education. We use the modern on-line learning techniques including interactive video simulation, discussion forums and quizzes.



https://www101.dcu.ie/registry/module_contents_archive_years_plus.php?function=2&subcode=NS466

# Staff Resources

https://www.guysandstthomas.nhs.uk/education-and-training/staff-training/barbaras-story.aspx

# Staff Resources

- DSIDC www.dsidc.ie
- The Early Identification of Memory Problems in Older Persons is an e-learning programme, available through HSE-land https://www.hse.ie/eng/about/who/cspd/ncps/older-people/resources/education/
- CANDEM study webinar: https://www.dementiaresearcher.nihr.ac.uk/midday-lecture-webinar-catch-up-the-cancer-care-needs-and-experiences-of-people-living-with-dementia/
- www.siog.org
- www.bgs.org.uk
- www.macmillan.org.uk
- MDTea podcasts – free podcasts for all HCPs working with older adults

# Discussion

1. What are the challenges you face in your current clinical practice?
2. What changes do you feel you can implement in your current practice?

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

# Thank You

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