



Caring for People with Dementia: a clinical practice guideline for the radiography workforce (imaging and radiotherapy)

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Summary

This clinical practice guideline is a comprehensive set of evidence-based recommendations for the whole radiographic workforce caring for people with dementia and their carers when undergoing imaging and/or radiotherapy. It has been developed systematically using the best available evidence from research and expert opinion, including service users, and subjected to peer professional, lay and external review. The guideline has recommendations for good practice for individual members of the radiographic workforce, service managers, academic institutions and the Society and College of Radiographers (SCoR).

1. Introduction

1.1 How was the topic identified?

The topic was debated at the Annual Delegate Conference (ADC) of the Society of Radiographers in May 2013; ADC motions 10 and 17. During the debate, delegates made clear their desire for advice and guidance for the radiographic workforce about providing better care for people with dementia who attend for imaging or radiotherapy.

1.2 Why is it important?

This topic is important both because of the prevalence of dementia, and the role of imaging and radiotherapy in the diagnosis and treatment of illness in so many people. It is vital that radiographers and other members of the radiographic workforce are able to understand and support the needs of people with dementia and their carers. Not only is this because all patients are entitled to the best possible, personalised care but, vitally, understanding and meeting the care needs of people with dementia will ensure the best outcomes from imaging and radiotherapy.

The incidence of dementia is increasing, particularly in the over 65s where the total population prevalence is 7.1%¹, and it is this group that is most likely to attend imaging and radiotherapy services. Diagnostic imaging is integral to most clinical diagnoses and is also increasingly being used in minimally-invasive therapeutic interventions. The total number of imaging examinations or tests carried out in England in 2012/13 was 41.1 million and over the past 10 years there has been a 39% increase, with the biggest growth being in MRI².

With regard to radiotherapy, in 2011 the number of new cases of cancer in the United Kingdom (UK) was 265,000 and four in ten people will receive a diagnosis of cancer at the present time. Access rates to radiotherapy nationally have been calculated at 38%, but it is estimated that, overall, 50% of people with cancer would benefit from a course of radiotherapy³.

1.3 How does it fit with existing radiographic practice?

The Society and College of Radiographers (SCoR) gives professional leadership to the radiographic workforce and offers advice and guidance that promotes patient-centred care and the highest quality services. The SCoR document library contains all of its policies, advice and guidance⁴. Of particular relevance is the Code of Professional Conduct 2013, Patient Advocacy 2008, Consent to Imaging and Radiotherapy Treatment Examinations 2007, Consent and Adults with Impaired Capacity 2010 and the Joint Response of the Society and College of Radiographers to the Final Report of the Independent Inquiry into care provided by Mid-Staffordshire NHS Foundation Trust, section 3, 2013.

1.4 The policy context

Government policies over the past 15 years have been directed towards improving the quality of health and social care services through a twin-track approach of implementing systems of clinical governance to ensure consistent high standards, and developing personalisation of care through a person-centred approach^{5,6,7}. 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.

This challenging agenda is being taken forward in the area of dementia care and treatment through a number of recent policies and actions. A National Dementia Strategy for England, published in 2009, set new standards for care⁸. A quarter of hospital beds are occupied by people with dementia and every hospital has been asked to commit to becoming dementia-friendly. Funding for hospital dementia risk assessments has been linked to the quality of care and all care homes and community services have been requested to sign up to the Dementia Care and Support Compact.

In Scotland, the Scottish Government Health Department (SGHD), in a national framework 'Reshaping Care for Older People'⁹, signalled its intention to fund initiatives that move care from institutions to home and the community. A key focus of the framework is the provision of care at home for people with dementia and greater support for carers. This has been elaborated within the Scotland's National Dementia Strategy¹⁰ and associated dementia care improvement programme.

Similar initiatives are occurring in Wales and Northern Ireland with the publication of strategy documents^{11,12} by the devolved administrations leading to programmes of action for service improvements for people with dementia and their carers.

In March 2012, the Prime Minister launched the Dementia Challenge. This set out plans to improve care in three aspects; increasing rates of diagnosis, improving the skills and awareness needed to support people with dementia and their carers and improving research. Progress is being overseen by three groups of champions each focussing on one of three main areas for action; driving improvements in health and care, creating dementia-friendly communities and improving dementia research.

A progress report in May 2013¹³ sets out the groups' shared ambition to 'make a real and positive difference to the lives of people affected by dementia'. It goes on 'We want to ensure that people with dementia and their carers receive high quality, compassionate care whether they are at home, in hospital or in a care home. We want the person with dementia, and their family and carer, to be at the heart of everything we do. We also want their wellbeing and quality of life to be first and foremost in the minds of those commissioning and providing services for them'.

Dementia is a world-wide issue and, in December 2013, the UK government hosted a G8 Dementia

Summit with the aim of developing co-ordinated global action. Ahead of this, The Alzheimer's Society and others offered their support for tackling dementia on a global scale, pointing out that there is no cure and few treatments and asking for it to be made a priority. As a result, the profile of dementia in the public's mind has increased significantly, the need for collaboration in delivering compassionate care has been prioritised and the government has announced that funding for research into finding treatments for dementia has doubled.

2. Scope and Purpose

Developing the guideline was prioritised and initiated by the SCoR Director of Professional Policy (DPP) in the autumn of 2013. Its broad purpose was to produce a practice guideline that both defines and supports the implementation of best practice when caring for people with dementia and their carers.

The proposed project was shared with members of the SCoR Public and Patient Liaison Group (PPLG) at the November 2013 meeting. It received their approval and two lay members of the PPLG agreed to take part in the development of the guideline as members of the stakeholder group.

The resulting practice guideline is for the whole radiographic workforce including students and learners. This encompasses clinical and non-clinical, registered and other practitioners, service managers, educationists and researchers. The population covered in the guideline is people with dementia-related conditions of varying severity and their carers. The setting for the guideline is imaging and radiotherapy departments in the United Kingdom.

3. Guideline objective and questions

The primary objective of the guideline was to produce evidence-based recommendations for best practice in radiographic services (imaging and radiotherapy) when caring for people with dementia and their carers. This objective encompassed a series of related questions to be answered about;

- the workforce's need for understanding dementia and its manifestations,
- optimising staff behaviours towards people with dementia,
- strategies for optimising the technical outcomes of interventions and improving patients' experience,
- suitability of the practice environment.

4. Guideline development process

4.1 The core group

The core group was brought together in November 2013 by the SCoR professional officer for policy, guidance and advice, under the direction of the DPP. The core group leader appointed is an independent education consultant and experienced academic radiographer and senior manager. Other members of the core group were a diagnostic radiographer who is a clinical-academic researcher with expertise in dementia, and the professional officer (policy guidance and advice).

4.2 The stakeholder group

The stakeholder group comprised 20 members; 7 clinical radiographers, 6 academic radiographers, 5 student radiographers and 2 service users. They were drawn from both imaging and radiotherapy communities across the UK. The service users were from the SCoR Public and Patient Liaison Group (PPLG) and other group members either volunteered or came forward as a result of an appeal in Synergy News, which is the SCoR monthly magazine. The names of both core and stakeholder group members are listed at the end of the document.

4.3 Peer review and consultation process and outcomes

A first draft of the recommendations was circulated to the stakeholder group for comment on 5th March 2014. Sixteen of the original 20 stakeholders responded and their comments were reviewed at core group meetings on 24th March and 2nd April 2014. In addition to the individual responses from lay members of the stakeholder group, two members of the core group attended the PPLG on 24th March to update them on progress to date and seek further feedback and support.

The comments were overwhelmingly positive with no dissent. Some stakeholders suggested additions because they did not appreciate that the recommendations should arise from the evidence. There was one negative response; the individual concerned questioned the need for a guideline that spelt out in detail how radiographers should care for patients. She interpreted it as an attack on their professionalism. The core group discussed this at their meeting on 24th March. They took the view that the author had misinterpreted the purpose of the recommendations and the core group leader responded appropriately.

The revised recommendations were merged with the draft practice guideline and this document received two separate expert external appraisals during May 2014. It was sent to The Alzheimer's Society for scrutiny and comment, which was also positive. After this, both the practice guideline and draft process manual were reviewed by an independent editorial consultant at a meeting with the DPP and core group. Following this, further improvements were made to both documents.

The finalised practice guideline was sent to three external reviewers, none of whom had had anything to do with its development. The reviewers completed a profoma (Process Manual Appendix H) and signed the conflict of interest declaration. The responses were considered by the core group and the final guideline document produced for UK Council approval.

4.4 Funding arrangements

The core group leader is an external contractor; an independent education consultant from a consultancy services company. She was paid as per contract. The clinical academic researcher was paid specifically to undertake the literature review but gave the remaining time to the core group voluntarily. Stakeholder group members and external reviewers gave their time and expertise voluntarily.

4.5 Conflict of interest

The SCoR policy and procedures for managing conflicts of interest was adhered to (Process Manual Appendix G). Members of the stakeholder group and external reviewers have signed 'conflict of interest' declarations and a list of their names and affiliations is appended. No conflicts of interest were declared. The declarations are available for public scrutiny.

4.6 SCoR approval process

The finalised practice guideline received approval from the UK Council of the SCoR in November 2014.

5. Guideline methodology

5.1 Literature Search

The literature search strategy was developed with the support of an NHS librarian using the following question 'What evidence is there to assist radiographers and others to give the best care to people with dementia and their carers when attending for imaging or radiotherapy?'

The topic did not conform to the PICO (Patient/Population, Intervention, Comparison, Outcome) framework as there was neither a specific intervention nor a specific comparison. Therefore it was decided to adapt this framework (Table 1 below) and keywords were listed under the domains of patient population, outcome and setting/professional group. An initial search identified a paucity of literature focussed on the imaging or radiotherapy setting in terms of this topic, and therefore the search was broadened to include all settings involving acute hospital services.

Table 1

Domain:	Patient Population	Outcome	Setting / professional group
Keywords	Dementia	Patient care	Radiographer
	Alzheimer's disease	Professional-patient relations	Radiotherapist
		Person centred care	Hospital
		Dignity	Acute hospital
		Communication	Allied health professional
		Quality of care	Nursing staff
			Ward

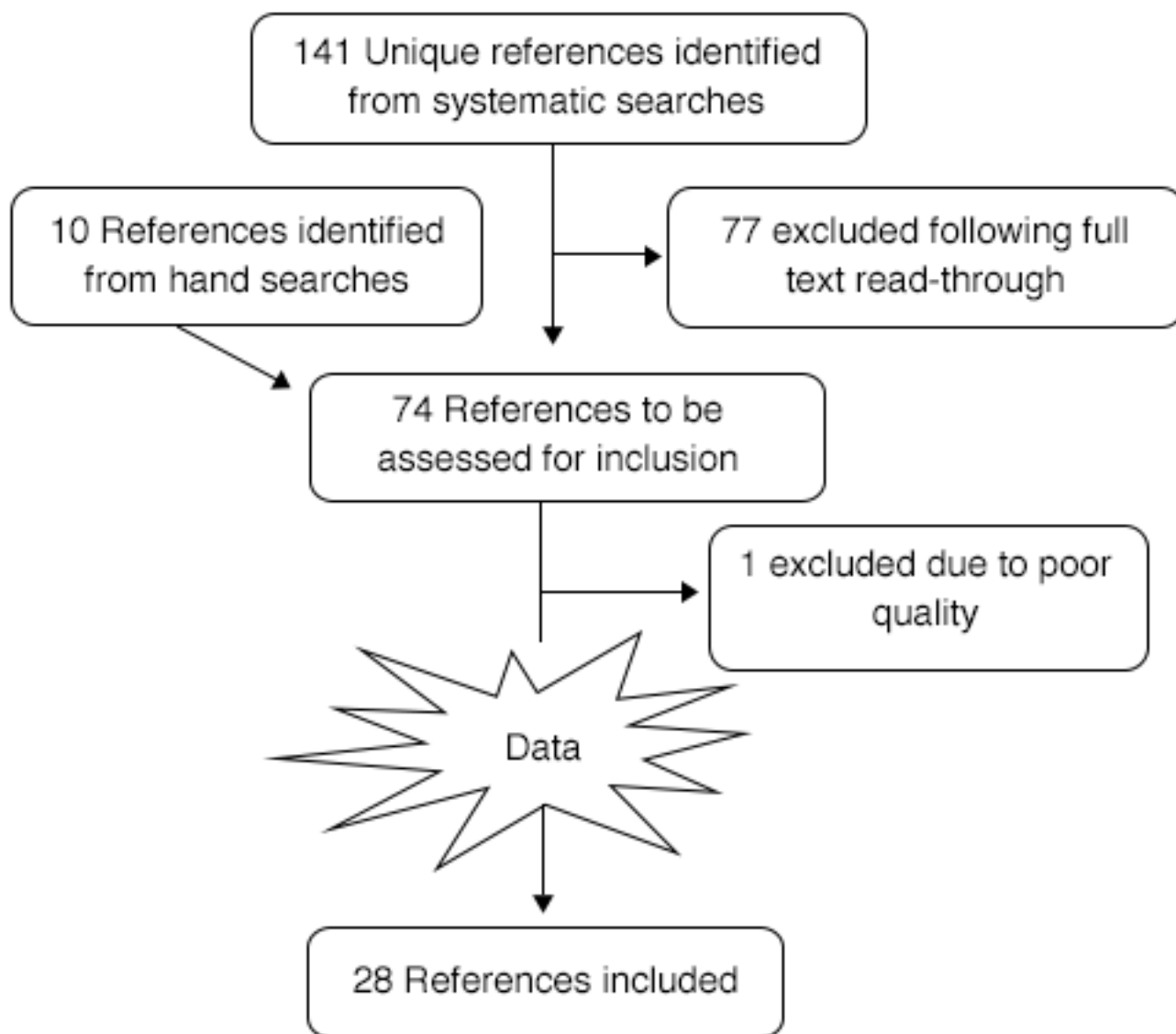
Further restrictions included English language, published between 1997 and 2013, humans, adults. The time period to search was decided based on the seminal work published by Kitwood¹⁴, which marked an attitudinal shift in dementia care. However, due to the volume of references identified this was further limited to a ten year period: 2003-2013. Searches were conducted using NHS Evidence and the following databases were searched independently: AMED, MEDLINE, CINAHL and Embase.

The search terms for each domain were used to identify MeSH headings, these differed between each database, and where no MeSH heading was available, free text was used. The explode function and truncation was used where it was deemed appropriate. The searches for each domain were combined using the Boolean operator 'OR' and to combine the different domains the Boolean operator 'AND' was used.

Inclusion was determined by reading the title and abstract to determine if a reference met the inclusion criteria, which was any article where the focus was on care of people with dementia in an acute care setting. Articles were excluded if their focus was on other care settings (e.g. community care, or long term care), if the main focus of the article was on diagnosis or design features rather than on patient care, and if the main focus of the article was on end-of-life care.

References were prioritised for reading by date of publication with the most recent receiving higher priority, and also by likely relevance to the radiography setting determined from the abstract. Data saturation was assessed by two members of the core group and once this was reached it was agreed that further inclusion was not necessary.

Fig 1 Outcome of literature search



5.2 Literature review

All articles were published in peer review journals, although the standard of the journals did vary from those that published primarily informal discussion articles, to those that mainly published primary research.

Of the included articles, 1 was a systematic review, 13 reported primary research findings, 12 were discussion papers and 2 reported case studies. Of the primary research articles 10 were qualitative studies, and 3 were quantitative, which reflects the nature of this specific topic which lends itself to qualitative enquiry. The research methods are outlined in table 2 below.

Table 2

Method	Number of articles
Survey	2
Pre-test/post-test	1
Focus groups	3
Observations/ethnography	3

Interviews	4
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Of those studies that recruited participants these included hospital staff/nursing students (8 studies), family carers of people with dementia (2 studies) and people with dementia (3 studies). The majority of the included studies were single site, or used multiple hospital sites within a single Trust. The majority of the research was conducted in the UK, with a single study emanating from each of the following countries: Australia, USA, Republic of Ireland and Canada. In terms of the discussion articles and case studies, the majority of those included focus on the UK healthcare system, with 1 focussing on care in the USA.

The quality of the discussion papers varied with some giving a clear justification for the inclusion of references and providing a comprehensive reference list, whilst others appeared to be less formal providing little detail about where references were found and limited bibliographies. However, as all of the discussion articles appeared to corroborate each other in terms of the general ideas on patient care that were being presented it was decided to include all of the discussion articles. Indeed, due to the nature of the topic and the importance of clinical experiences and the practical application of patient care techniques it was felt that these articles, along with the case study articles, could provide valuable supporting information for this guidance document as they often drew upon the authors clinical experiences and had a practical focus.

5.3 Description of how recommendations were developed

The core group leader and clinical-academic researcher met to consider the evidence and develop the recommendations for the practice guideline. Each article had been summarised using the data extraction tool (Appendix D in the Process Manual). These were reviewed and a judgement made about their quality and value. This enabled a list of raw recommendations to be compiled together with the associated evidence source.

The core group leader undertook a thematic analysis of the raw recommendations, selecting themes according to the initial guideline questions in 3 above and allocating recommendations to these, removing any duplication whilst retaining the source reference details. During this process it became apparent that some themes required further expansion; for example, optimising staff behaviours needed to be disaggregated into specific sections about training needs and relationship building. This draft was circulated to remaining core group members for further comment and refinement prior to undertaking the consultation process outlined in 4.3 above.

The application of GRADE for each individual recommendation within this practice guideline was considered by core group. However, due to the limitations of GRADE, which cannot be applied where a topic area has no clear outcome measures or obvious comparison approaches¹⁵, it was rejected. It is acknowledged by the authors that the body of evidence in this area is not strong, comprising mostly of expert opinion in the form of discussion papers and small single centre observational studies.

5.4 Limitations of the guideline including consideration of possible bias

In terms of the strength of the recommendations contained within this guideline, no contradictory evidence was identified with a strong level of agreement between all sources. The sources from which each recommendation was drawn are highlighted throughout the document. One limitation of the evidence that informed these guidelines is that none of it focussed specifically on the radiography setting. However, the guideline development core group universally agreed that the similarities with other settings in the acute hospital are sufficient to allow for the application of this evidence within radiography.

6. Dementia facts

At the current estimated rate of prevalence, there will be 850,000 people with dementia in the UK in 2015¹⁴. One in three people over 65 will develop dementia, and two-thirds are women. This figure is increasing because people are surviving historic killers such as heart disease and cancer and living longer. It is estimated that, by 2021, the number of people with dementia in the UK will have increased to around 1 million and doubled by 2040^{15,16}.

Dementia is a syndrome associated with an ongoing decline of the brain and its abilities. Alzheimer's disease is the commonest cause but there are others, such as vascular dementia¹⁷. Symptoms include problems with memory, thinking speed, mental agility, language, understanding and judgement. People with dementia can become apathetic or uninterested in their usual activities, and may have problems expressing and managing their emotions, especially in relation to an inability to fully process or communicate what they are thinking or what they want.

Individuals with these conditions may also find social situations challenging, lose interest in socialising, and aspects of their personality may change. A person with dementia may lose empathy or believe things that are untrue. As dementia affects a person's mental abilities, they may also find decision making, planning and organising difficult. Maintaining independence may also become a problem¹⁸.

People with dementia are not a homogenous group, not all the symptoms manifest in each person or in the same way. The severity of symptoms may vary and progress over time. In addition there are a range of other factors that can influence how an individual experiences dementia; including their personality, biography, physical health, environment, and social and cultural factors¹⁹.

Scientists understand less about dementia than they do about heart disease or cancer and there is no cure at the present time, although, if it is detected early, there are ways of slowing down the deterioration and maintaining mental function. The challenge for healthcare workers and others is to support people living with dementia and their carers to manage symptoms and live as well as possible. Each person should be treated as an individual by radiography staff, whilst at the same time contextualising their experience within a broad understanding of the symptoms of dementia and how these may present difficulties within the radiography environment.

7. Guideline Recommendations

The recommendations are divided into specific sections related to the guideline objective and related questions in 3 above.

1. The practice environment -acknowledging the need for special provision

1.1 The environment in the department should be adjusted by removing excess stimuli and ensuring that it is calm and well organized when patients with dementia arrive for imaging or treatment (Heath et al 2010, McGilton et al 2007, Moyle et al 2008).

1.2 The organisational culture of departments should be flexible and enabling, value good practice and support person-centred care (Bailliee 2012b, Cunningham & Archibald 2006, Webster 2011).

1.3 Departments should seek feedback from patients and carers about their experiences and act accordingly.

1.4 Departments should liaise with people with dementia and/or their carers about appointment times to mitigate factors that might increase stress and try to avoid compromising their normal routines (Andrews 2012, McCloskey 2004, McGilton et al 2007, Moyle et al 2008, Mowbray 2010).

1.5 Departments should consider utilising forms of therapy that may provide reassurance such as

music, which may be brought in by the patient, or reminiscence; inviting patients and carers to bring items such as photographs to be discussed prior to examination or treatment (Clisset 2013, McCloskey 2004).

1.6 Departments should investigate the use of identifiers such as forget me not, blue wrist bands or butterflies for in-patients (and outpatients where it allows) (Andrews 2012, Duffin 2013).

1.7 More time should be allowed to perform procedures since this can reduce the need for restraint (Borbasi et al 2006, Mowbray 2010).

1.8 Departments should create the role of dementia champion supported by appropriate training (Borbasi et al 2006, Chater 2013, Crabtree 2010).

1.9 Departments should consider using appropriately trained volunteers as advocates for people with dementia (Borbasi et al 2006, Galvin 2010).

1.10 Departments should offer support for staff (professional supervision) in recognition of the emotional burden associated with providing dementia-related care (Andrews 2012, Baillee 2012b, Bridges 2011).

1.11 The organisation's management information system (MIS) should support all staff to be fully informed of the patient's diagnosis (Armstrong 2011).

2. Building relationships with patients and carers to optimise the patient experience (Baillee 2012, McGilton et al 2007, Nolan 2006)

2.1 Acknowledge that people with dementia have both physical and psychological needs (Clissett 2013).

2.2 Provide a patient information pack that has been designed specifically for people with dementia and their carers *in advance* and involve lay people in writing it (Chater 2013, Mowbray 2010).

2.3 Encourage patients to bring music, a 'This is Me' document or other kind of reassuring material when attending the department (Baillee 2012, Heath et al 2010).

2.4 Ensure that the patients are accompanied by a familiar person, such as a nurse or informal carer (Chater 2013).

2.5 Work collaboratively with patients and their carers, maintaining the dignity and autonomy of the person at all times (Bridges 2011, Nolan 2006, Webster 2011).

2.6 Work collaboratively with other professionals in the patient's pathway, sharing experiences, encouraging dialogue and disseminating best practice; learning from each other to share knowledge of the patient (Bridges 2011, Chater 2013).

3. Strategies for optimising communication with people with dementia and their carers

3.1 Liaise with caregivers and/or people with dementia about appointment times (Andrews 2012, McCloskey 2004, McGilton et al 2007, Moyle et al 2008, Mowbray 2010.).

3.2 Keep the number of professional practitioners in the room to a minimum with one person taking the lead.

3.3 Observe and value both verbal and non-verbal communication and always assume that some communication is possible (Cowdell 2010, Nolan 2006).

3.4 Treat patients as equal partners in communication even when communication is limited (Nolan 2006).

3.5 Approach patients calmly, gently and in a relaxed manner.

3.6 Find out and use the patient's preferred name (Bridges 2011).

3.7 Ensure you have the patient's attention before giving important information.

3.8 Speak directly to the patient even if they are unable to respond, and keep eye contact.

3.9 Speak plainly and avoid complicated idioms of speech (Heath et al 2010).

3.10 Use short, simple sentences and a soft tone.

3.11 Ask simple questions that require a short answer, e.g. yes/no.

3.12 Allow ample response time before repeating information.

3.13 Repeat sentences using the same words.

3.14 Ensure that interactions are not ended abruptly (Clissett 2013).

3.15 Remain calm if patient becomes agitated.

3.16 Avoid moving or walking around during conversation.

3.17 Model the desired behaviour.

4. Understanding patients' behaviour and adopting positive ways to reduce distressed reactions

4.1 Be aware that patients' behaviour is a form of communication and recognise that withdrawal or passivity is a form of distressed reaction (Norman 2006).

4.2 Patients may exhibit distressed behaviours due to pain, fatigue, hunger or other discomfort; try to identify the cause of distressed reactions and avoid compromising normal routine activities (Clissett 2013, Galvin 2010, McGilton et al 2007).

4.3 Accept that people with dementia may have their own sense of reality and that challenging this may cause distress.

4.4 Utilise forms of therapy that may provide reassurance such as music, which may be brought in by the patient, or reminiscence; inviting patients and carers to bring items such as photographs to be discussed prior to examination or treatment (Clissett 2013, McCloskey 2004).

4.5 The use of restraint should be the last resort; it can present risks to the patient (and others) and should not be used just because not enough staff are available (Chater 2013, Gallagher 2011, Galvin 2010).

4.6 Identify safe ways to facilitate walking; this can reduce agitation and assist patient safety. Walking in a circular route can decrease agitation (Andrews 2012, Galvin 2010).

4.7 Use diversion or distraction techniques to create a suitably stimulating environment and gain cooperation (Clissett 2013, King 2012). These could include;

Repetitive and familiar tasks e.g. sorting buttons (King 2012),

Use of reminiscence,

Use of all senses: touch – sensory box, textures, tactile stimulation, hearing - personalised music, calming music, sight - visual way-finding cues and lighting (Clissett 2013, King 2012),

Ask a family member to talk soothingly throughout the procedure (intercom),

5. Carer involvement

5.1 Family members and informal caregivers should be involved in care and considered assets (Andrews 2012, Baillie 2012, Borbasi et al 2006, Clissett 2013b, Heath et al 2010, Jurgens 2012), McGilton et al 2007, Moyle et al 2008, Nolan 2006, Webster 2011) .

5.2 Carers should be viewed as a source of expertise (Clissett 2013b).

5.3 Staff should work collaboratively with patients and carers (Bridges 2011, Webster 2011).

5.4 Staff should acknowledge that carers may also need information and reassurance and should avoid adopting a defensive or confrontational approach to them (Nolan 2006, Jurgens 2012).

6. Staff skills and attitudes

People with dementia and their carers coming to the imaging or radiotherapy department may have additional needs that may challenge staff skills and attitudes.

6.1 Consider that the lives of people with dementia are meaningful, do not assign blame to the patient (Nolan 2006).

6.2 Challenge ‘us and them’ attitudes (Cowdell 2010).

6.3 Be non-judgemental and show unconditional positive regard for patients and their carers (McCloskey 2004).

6.4 Do not lose sight of the person and avoid dehumanising behaviours (Cunningham & Archibald 2006, McCloskey 2004).

6.5 Appreciate that you can learn from people with dementia (Cowdell 2010)

6.6 Recognise and act on patient cues regarding unmet needs and distressed reactions (Dewing 2010, Heath et al 2010, McCloskey 2004)).

6.7 Use initial introduction and identity check to assess the patient’s level of understanding.

6.8 Request consent and do not assume it in cases where express written consent is not required (Bridges 2011).

6.9 Modify information provided to the patient to include only that which is commensurate with informed consent and directly related to the activity and ensuring safety (McCloskey 2004).

6.10 View family members and/or informal caregivers as assets and involve them in care (Andrews 2012, Baillie 2012, Borbasi et al 2006, Clissett 2013b, Heath et al 2010, Jurgens 2012), McGilton et al 2007, Moyle et al 2008, Nolan 2006, Webster 2011).

6.11 Have an attitude of warmth and firmness (Heath et al 2010).

6.12 Employ flexible approaches and be creative (Baillie 2012).

6.13 Be a reflective practitioner, interrogating your own behaviours and attitudes towards people with dementia.

6.14 Engage in team-based reflection (Chater 2013).

7. Training needs

7.1 All staff, clinical and non-clinical, should have additional training and development in dementia-related care (Baillie 2012b, Dewing 2010). This should challenge dysfunctional cultural norms and include the emotional, social, intellectual and practical aspects of care.

7.2 Specialist training for the role of dementia champion should be sought.

7.3 People with dementia and their carers should be involved in training and development opportunities for staff.

7.4 Development opportunities should be as interactive as possible to encourage reflective practice and use a variety of learning and teaching strategies including observation, case studies and group discussions (Cowdell 2010, Norman 2006).

7.5 Dementia-related education should be available at pre-registration and post-registration (CPD) levels and continually revisited (Baillie 2012b, Dewing 2010).

7.6 The following list of topics is considered essential but is not exhaustive (Gandesha 2012, Leung 2010)

- responding to behaviour that challenges
- person-centred care (Crabtree 2010)
- reminiscence and life stories
- the legal framework of consent
- capacity and consent – Mental Capacity Act (Mowbray 2010)
- deprivation of liberty (DoLS)
- best interests
- safeguarding vulnerable adults
- human rights, dignity, autonomy, wellbeing
- types of restraint; physical, chemical, mechanical, technological, psychological (Gallagher 2011)
- pain assessment and recognising pain (Galvin 2010, Gandesha 2012)
- theories and case studies of dementia care
- models of ethical decision making (Gallagher 2011)
- models of reflection and interrogating the self (Heath et al 2010, Moyle et al 2008)

The following theoretical frameworks and models were identified in the literature reviews as useful ways for practitioners and others to understand and interpret the evidence.

- Kitwood's (1997) enhancers and detractors.
- PLST Conceptual Model for people with Alzheimer's disease.
- Hall and Buckwater's (1987) Model for understanding stress thresholds and their reduction.
- Antecedents, Behaviour, Consequences (ABC) Tool for understanding behaviour - a reflective tool for practitioners to understand the effect of the environment on behaviour.
- Nolan, M. et al's (2006) The Senses Framework: Improving Care for Older People through a Relationship-Centred Approach. GRIP: University of Sheffield.
- Li et al's (2003) CARE - Creating Avenues for Relative Empowerment. A programme for improving self- efficacy for care givers.

8. Implementation

8.1 implementation and dissemination

The SCoR will disseminate the guideline through its networks. These include regular meetings of managers and conference and study days.

In addition, the core group has developed the following resources;

A summary document outlining the rationale and key recommendations,

Implementation guidance for managers, including resource implications and potential barriers to implementation.

e learning module, Dementia, developed by a core group member, is available on the eLearning for health website, free of charge to all NHS organisations www.e-lfh.org.uk

8.2 Impact measures and audit tools

All employing authorities are required to have governance arrangements in place that include locally developed audit tools for patient experience. It is expected that these will be adapted to measure the impact of the practice guideline recommendations on patients' and carers' experience. An audit check list can be found in the supplementary, supporting information. This is in addition to the national patient experience survey that all NHS organisations take part in.

8.3 Organisational or financial barriers to implementation

The majority of the recommendations have no financial implications. There is a requirement for additional training and some additional resources, which will require budgeting for. These could include changes to ICT systems.

The main block to implementation is likely to be organisational and cultural since some recommendations require changes to established working practices. However, many departments are working through the changes needed to embed person-centred care more fully into daily practice and this guideline's recommendations should be integral to this process.

9. Recommendations for future research

The authors have acknowledged the relatively low quality of the evidence base for the guideline and this provides many opportunities for redress. In particular, the lack of any published evidence from the radiographic setting needs to be addressed.

10. Date of publication, review and updating

January 2015

Three-yearly review unless an earlier review is indicated. This may be required because of changes in policy or published evidence that indicates a need for the practice guideline to be updated. Policy changes are monitored and reviewed by the SCoR team of professional staff. The core and stakeholder groups comprised people with a special interest in dementia, including staff in imaging and radiotherapy departments who are dementia champions. They will be surveyed annually to ask if they are aware of changes to the evidence base that may trigger an early review and update of the practice guideline.

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12. Appendices

Appendix 1 Dementia Guideline Evidence References

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Appendix 2 Names and affiliations of guideline core and stakeholder groups

Core Group

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13. Supplementary Supporting Information

Audit checklist

Data extraction template references

External reviewers' feedback

Implementation guidance and advice for managers

Minutes of PPLG meetings November 2013, May 2014

Summary document

Caring for People with Dementia guideline - Audit Checklist

Caring for People with Dementia: a clinical practice guideline for the radiography workforce (imaging and radiotherapy) January 2015

Introduction

The clinical practice guideline, caring for people with dementia and their carers when attending for imaging or radiotherapy has been approved by United Kingdom Council of the Society and College of Radiographers (SCoR). It can be found within their policy and document library ¹.

All employing authorities are required to have governance arrangements in place that include locally developed audit tools for patient experience. This check list has been provided to assist imaging and radiotherapy departments to adapt their audits to measure the impact of the practice guideline recommendations on patients' and carers' experience. **The check list is not exhaustive nor is it intended to be a replacement for local audit measures. It contains suggestions for inclusion of some of the measurable aspects of the guideline recommendation.**

Checklist Themes

The guideline contains recommendations under 7 themes, which you may find useful when developing and adapting audit tools:

1. The practice environment –acknowledging the need for special provision;
2. Building relationships with patients and carers to optimise the patient experience;
3. Strategies for optimising communication with people with dementia and their carers;

4. Understanding patients' behaviour and adopting positive ways to reduce distressed reactions;
5. Carer involvement;
6. Staff skills and attitudes;
7. Training needs.

Specific measures

- Type and extent of any therapies used; e.g. music, which may be brought in by the patient, or reminiscence; inviting patients and carers to bring items such as photographs to be discussed prior to examination or treatment
- System of identifiers in place, such as 'forget me not', blue wrist bands or butterflies
- Dementia champion role identified and/or established
- Numbers of volunteers
- System of professional supervision
- Patient information pack designed specifically for people with dementia and their carer
- Information provided to the patient to gain informed consent has been modified to include only that which is directly related to the activity and ensuring safety
- Numbers of staff, clinical and non-clinical who have received additional training and development in dementia-related care
- People with dementia and their carers are involved in training and development opportunities for staff

References

1. Caring for People with Dementia: a clinical practice guideline for the radiography workforce (imaging and radiotherapy). The Society and College of Radiographers (SCoR), January 2015
<http://www.sor.org/learning/document-library>
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Caring for People with Dementia guideline - Implementation Guidance

Caring for People with Dementia: a clinical practice guideline for the radiography workforce (imaging and radiotherapy) January 2015

Implementation Guidance for Service Managers

1. Purpose

1.1 This guidance has been written to assist service managers with the implementation of the recommendations contained within the clinical practice guideline; caring for people with dementia and their carers when attending for imaging or radiotherapy. The full guideline has been approved by United Kingdom Council of the Society and College of Radiographers (SCoR) and is available within their policy and document library 1.

1.2 The recommendations represent best practice for the whole radiographic workforce caring for people with dementia and their carers at the time of publication. They have been developed systematically using the best available evidence from research and expert opinion, including service users, and subjected to peer professional, lay and external review.

1.3 The SCoR acknowledges that radiographers and other health workers are accountable for the quality of their practice and some of the recommendations relate specifically to individuals and their personal, professional development. However, the context and culture of the organisation within which radiographers work directly influences their capacity to practice well. Therefore some recommendations in the practice guideline concern the organisation's culture, systems and processes, both at department level and within the whole organisation.

1.4 This document is intended to be helpful and supportive to managers in the role of middle leaders in large organisations with many competing priorities. It is acknowledged that implementation will take time and be the subject of negotiation and compromise. Nevertheless, the recommendations represent best practice and should become embedded over time.

2. Creating a Dementia Action Plan

2.1 This document should be developed to guide the implementation of the practice guideline. This has seven themes and it is recommended that managers structure the action plan according to these. The creation of the action plan will enable managers to identify the resources; human, financial and other, that will be needed and include them in business plans.

2.2 Theme 1, The Practice Environment

Patients with dementia have particular needs that are likely to mean that more time is needed for interventions and the clinical environment requires some adjustments. This includes ensuring that the systems and processes in departments are fit for purpose. In addition, the culture in the department should be one that encourages and inspires staff to practise in respectful, compassionate, patient-centred ways. The appointment of a Dementia Champion is highly

recommended. This person can advocate for patients with dementia, assist with developing the action plan, lead any changes needed and cascade good practice.

2.3 Theme 2, Building Relationships with Patients and Carers

This group of recommendations deepens the building of relationships with patients and their carers beyond what is normally anticipated in imaging and radiotherapy. People with dementia need additional preparation prior to attending and patient reinforcement and reassurance during their visit. Greater collaboration with formal and informal caregivers is also needed to ensure that care is personalised and interventions and examinations more likely to be successful. The dementia action plan should identify how these will be met and prioritise any additional resources required.

2.4 Theme 3, Strategies for Optimising Communication

Good communication is a fundamental aspect of good care and the recommendations in this section do not go beyond what should be good practice for all patients attending for imaging and radiotherapy. The dementia action plan should detail how communication strategies for people for dementia will be appropriately customised.

2.5 Theme 4, Understanding Patients' Behaviour; adopting positive ways to reduce distressed reactions

People with dementia may become distressed about attending for imaging or radiotherapy. Their condition may cause them to exhibit atypical distressed reactions. Staff need appropriate training to understand these and develop a range of strategies for mitigating them. Liaising with carers is the best way of finding out how an individual patient exhibits distress and can be helped to cope with it. On rare occasions, restraint may be necessary but this must always be a last resort. The dementia action plan should identify types of restraint and situations where it may safely be used.

2.6 Theme 5, Carer Involvement

Carers are often the best resource that the department has for enabling successful imaging or radiotherapy. Staff must work in partnership with carers and see them an important resource. The dementia action plan should reflect this and any associated training needs

2.7 Theme 6, Staff Skills and Attitudes

Imaging and treating people with dementia can challenge staff professionalism and this must be acknowledged in the dementia action plan together with identified staff development.

2.8 Theme 7, Training Needs

This section identifies the additional training and development needs for dementia-related care. The dementia action plan should contain a section that demonstrates what training will be offered, to whom and over what period of time.

3. Organisational and Financial Implications

3.1 Implementing these measures will cause time spent with patients to increase, although carers and volunteers can play a big part if used appropriately. Managers will need to review this within their overall department business plans. If changes to systems and processes are identified, this could result in the need for alterations to ICT systems.

3.2 The appointment of a dementia champion will incur training costs but that person will be an invaluable resource for departments, especially through cascading training and development.

3.3 Some additional resources such as preparing an induction pack or reviewing a system of patient identifiers could be a CPD task for an interested member of staff.

3.4 All staff are required to undertake CPD for their professional development and the training and development identified in the dementia action plan can form part of staff CPD activities.

3.5 The main block to implementation is likely to be organisational and cultural since some recommendations require changes to established working practices. However, many departments are working through the changes needed to embed person-centred care more fully into daily practice and this guideline's recommendations should be integral to this process.

3.6 Guideline implementation will need regular auditing; an audit checklist has been included in the practice guideline to assist with this.

4. References

1. Caring for People with Dementia: a clinical practice guideline for the radiography workforce (imaging and radiotherapy). The Society and College of Radiographers (SCoR), January 2015
<http://www.sor.org/learning/document-library>

Caring for People with Dementia guideline - Summary

Caring for People with Dementia: a clinical practice guideline for the radiography workforce (imaging and radiotherapy) January 2015

1. Introduction

1.1 This document summarises the outcomes of the clinical practice guideline for caring for people with dementia and their carers when attending for imaging or radiotherapy. The full guideline has

been approved by United Kingdom Council of the Society and College of Radiographers (SCoR) and is available within their policy and document library ¹.

1.2 The recommendations represent best practice for the whole radiographic workforce caring for people with dementia and their carers at the time of publication. They have been developed systematically using the best available evidence from research and expert opinion, including service users, and subjected to peer professional, lay and external review.

1.3 This topic is important both because of the prevalence of dementia, and the role of imaging and radiotherapy in the diagnosis and treatment of illness in so many people. The incidence of dementia is increasing, particularly in the over 65s where the total population prevalence is 7.1%², and it is this group that is most likely to attend imaging and radiotherapy services. It is therefore vital that radiographers and other members of the radiographic workforce are able to understand and support the needs of people with dementia and their carers in order to deliver the best possible, personalised care and ensure the best outcomes from imaging and radiotherapy.

2. Guideline Purpose

2.1 The purpose of developing the guideline was to produce evidence-based recommendations for best practice in radiographic services (imaging and radiotherapy) when caring for people with dementia and their carers.

2.2 The resulting document contains recommendations under 7 themes; some of which are simple to implement while others are more challenging. The themes are:

1. The practice environment –acknowledging the need for special provision;
2. Building relationships with patients and carers to optimise the patient experience;
3. Strategies for optimising communication with people with dementia and their carers;
4. Understanding patients’ behaviour and adopting positive ways to reduce distressed reactions;
5. Carer involvement;
6. Staff skills and attitudes;
7. Training needs.

3. Specific Recommendations

1. The practice environment –acknowledging the need for special provision

1.1 The environment in the department should be adjusted by removing excess stimuli and ensuring that it is calm and well organized when patients with dementia arrive for imaging or treatment.

1.2 The organisational culture of departments should be flexible and enabling, value good practice and support person-centred care.

1.3 Departments should seek feedback from patients and carers about their experiences and act accordingly.

1.4 Departments should liaise with people with dementia and/or their carers about appointment times to mitigate factors that might increase stress and try to avoid compromising their normal routines.

1.5 Departments should consider utilising forms of therapy that may provide reassurance such as music, which may be brought in by the patient, or reminiscence; inviting patients and carers to bring items such as photographs to be discussed prior to examination or treatment.

- 1.6 Departments should investigate the use of identifiers such as forget me not, blue wrist bands or butterflies for in-patients (and outpatients where it allows).
- 1.7 More time should be allowed to perform procedures since this can reduce the need for restraint.
- 1.8 Departments should create the role of dementia champion supported by appropriate training.
- 1.9 Departments should consider using appropriately trained volunteers as advocates for people with dementia.
- 1.10 Departments should offer support for staff (professional supervision) in recognition of the emotional burden associated with providing dementia-related care.
- 1.11 The organisation's management information system (MIS) should support all staff to be fully informed of the patient's diagnosis.

2. Building relationships with patients and carers to optimise the patient experience

- 2.1 Acknowledge that people with dementia have both physical and psychological needs.
- 2.2 Provide a patient information pack that has been designed specifically for people with dementia and their carers *in advance* and involve lay people in writing it.
- 2.3 Encourage patients to bring music, a 'This is Me'³ document or other kind of reassuring material when attending the department.
- 2.4 Ensure that the patients are accompanied by a familiar person, such as a nurse or informal carer.
- 2.5 Work collaboratively with patients and their carers, maintaining the dignity and autonomy of the person at all times.
- 2.6 Work collaboratively with other professionals in the patient's pathway, sharing experiences, encouraging dialogue and disseminating best practice; learning from each other to share knowledge of the patient.

3. Strategies for optimising communication with people with dementia and their carers

- 3.1 Liaise with caregivers and/or people with dementia about appointment times.
- 3.2 Keep the number of professional practitioners in the room to a minimum with one person taking the lead.
- 3.3 Observe and value both verbal and non-verbal communication and always assume that some communication is possible.
- 3.4 Treat patients as equal partners in communication even when communication is limited.
- 3.5 Approach patients calmly, gently and in a relaxed manner.
- 3.6 Find out and use the patient's preferred name.
- 3.7 Ensure you have the patient's attention before giving important information.
- 3.8 Speak directly to the patient even if they are unable to respond, and keep eye contact.

3.9 Speak plainly and avoid complicated idioms of speech.

3.10 Use short, simple sentences and a soft tone.

3.11 Ask simple questions that require a short answer, e.g. yes/no.

3.12 Allow ample response time before repeating information.

3.13 Repeat sentences using the same words.

3.14 Ensure that interactions are not ended abruptly.

3.15 Remain calm if patient becomes agitated.

3.16 Avoid moving or walking around during conversation.

3.17 Model the desired behaviour.

4. Understanding patients' behaviour and adopting positive ways to reduce distressed reactions

4.1 Be aware that patients' behaviour is a form of communication and recognise that withdrawal or passivity is a form of distressed reaction.

4.2 Patients may exhibit distressed behaviours due to pain, fatigue, hunger or other discomfort; try to identify the cause of distressed reactions and avoid compromising normal routine activities.

4.3 Accept that people with dementia may have their own sense of reality and that challenging this may cause distress.

4.4 Utilise forms of therapy that may provide reassurance such as music, which may be brought in by the patient, or reminiscence; inviting patients and carers to bring items such as photographs to be discussed prior to examination or treatment.

4.5 The use of restraint should be the last resort; it can present risks to the patient (and others) and should not be used just because not enough staff are available.

4.6 Identify safe ways to facilitate walking; this can reduce agitation and assist patient safety. Walking in a circular route can decrease agitation.

4.7 Use diversion or distraction techniques to create a suitably stimulating environment and gain cooperation. These could include; repetitive and familiar tasks e.g. sorting buttons, use of reminiscence, use of all senses: touch – sensory box, textures, tactile stimulation, hearing - personalised music, calming music, sight - visual way-finding cues and lighting and asking a family member to talk soothingly throughout the procedure (intercom).

5. Carer involvement

5.1 Family members and informal caregivers should be involved in care and considered assets.

5.2 Carers should be viewed as a source of expertise.

5.3 Staff should work collaboratively with patients and carers.

5.4 Staff should acknowledge that carers may also need information and reassurance and should avoid adopting a defensive or confrontational approach to them.

6. Staff skills and attitudes

People with dementia and their carers coming to the imaging or radiotherapy department may have additional needs that may challenge staff skills and attitudes.

6.1 Consider that the lives of people with dementia are meaningful, do not assign blame to the patient.

6.2 Challenge 'us and them' attitudes.

6.3 Be non-judgemental and show unconditional positive regard for patients and their carers.

6.4 Do not lose sight of the person and avoid dehumanising behaviours.

6.5 Appreciate that you can learn from people with dementia.

6.6 Recognise and act on patient cues regarding unmet needs and distressed reactions.

6.7 Use initial introduction and identity check to assess the patient's level of understanding.

6.8 Request consent and do not assume it in cases where express written consent is not required.

6.9 Modify information provided to the patient to include only that which is commensurate with informed consent and directly related to the activity and ensuring safety.

6.10 View family members and/or informal caregivers as assets and involve them in care.

6.11 Have an attitude of warmth and firmness.

6.12 Employ flexible approaches and be creative.

6.13 Be a reflective practitioner, interrogating your own behaviours and attitudes towards people with dementia.

6.14 Engage in team-based reflection.

7. Training needs

7.1 All staff, clinical and non-clinical, should have additional training and development in dementia-related care. This should challenge dysfunctional cultural norms and include the emotional, social, intellectual and practical aspects of care.

7.2 Specialist training for the role of dementia champion should be sought.

7.3 People with dementia and their carers should be involved in training and development opportunities for staff.

7.4 Development opportunities should be as interactive as possible to encourage reflective practice and use a variety of learning and teaching strategies including observation, case studies and group discussions.

7.5 Dementia-related education should be available at pre-registration and post-registration (CPD) levels and continually revisited.

7.6 The following list of topics is considered essential but is not exhaustive:

- responding to behaviour that challenges
- person-centred care
- reminiscence and life stories
- the legal framework of consent
- capacity and consent – Mental Capacity Act
- deprivation of liberty (DoLS)
- best interests
- safeguarding vulnerable adults
- human rights, dignity, autonomy, wellbeing
- types of restraint; physical, chemical, mechanical, technological, psychological
- pain assessment and recognising pain
- theories and case studies of dementia care
- models of ethical decision making
- models of reflection and interrogating the self

4. Conclusion

4.1 The majority of the recommendations have no financial implications but they do require staff to be fully engaged with the needs of this particular group of patients and for the organisation to acknowledge that changes to systems and processes may be needed, both at department and organisation levels.

4.2 There is a requirement for additional training and some additional resources, which will have to be budgeted for. It is recommended that departments identify a dementia champion to lead the implementation. All of these changes will take time and need auditing; an audit checklist has been included in the practice guideline to assist with this.

5. References

1. Caring for People with Dementia: a clinical practice guideline for the radiography workforce (imaging and radiotherapy). The Society and College of Radiographers (SCoR), January 2015
<http://www.sor.org/learning/document-library>
2. Dementia UK: second edition. The Alzheimer's Society
3. This is me document. RCN and The Alzheimer's Society
http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1604 [accessed 24.11.14]

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