### Using play-based strategies to enhance the patient experience for people with dementia.



## **POWER PLAY**

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ealth professionals working in radiographic services (imaging and radiotherapy), as elsewhere, face the daily challenge of delivering services which are designed to respond to individual patient need! Increasingly, in our ageing society?, health professionals meet significant numbers of individuals who are living with a diagnosis of dementia – either as a patient, family member or carer3.

In 2015, the Society and College of Radiographers (SCoR) published clinical practice guidance for the radiography workforce covering how to care for people with dementia<sup>1</sup>. Section 3 of the SCoR guidance sought to provide 'evidence-based recommendations for best practice in radiographic services (imaging and

radiotherapy)' and outlined a series of inter-related questions to identify how this could be achieved most effectively. Two of these questions focused on:

- Strategies for optimising the technical outcomes of interventions and improving the patient's experience.
- Suitability of the practice environment.

This article addresses both of these questions with reference to examples from the clinical practice guideline. It discusses how the application of play-based techniques and resources can contribute to the provision of imaging and radiotherapy services that are responsive to, and supportive of, the needs of people who have

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dementia and of the carers who look after them. The article has three central themes, which explore the building of relationships, communication as a means of connection, and the role of the environment.

#### BACKGROUND

Dementia is defined as a 'clinical syndrome of cognitive decline that is sufficiently severe to interfere with social or occupational functioning'4 and typically describes a broad set of symptoms which include memory-loss and difficulties with thinking, problem-solving or language<sup>5</sup>. Dementia is caused when the brain becomes damaged by disease, such as Alzheimer's disease, or by a series of strokes<sup>5</sup>. It is a progressive condition, which means the symptoms will gradually get worse, presenting an ever-changing set of challenges for those affected patients, family and the wider community. Green and Lakey<sup>6</sup> surveyed 500 people with dementia and found that 66% had identified psychological and emotional barriers that inhibit their ability to cope, citing a lack of confidence as well as anxiety about becoming confused, as significant barriers to their participation in activities. The unfamiliarity of the healthcare environment, coupled with its expectations of competence and cooperation, are likely to exacerbate these effects, increasing stress and feelings of vulnerability in the elderly patient.

There are currently 850,000 people living with dementia in the UK<sup>7</sup> and, whilst the rate of increase in prevalence may not be as high as previously thought<sup>8</sup>, it is estimated that by 2050 the number of people living with a diagnosis of dementia will reach two million°. This global health concern, which affects 47 million people worldwide¹0, has a huge social and economic impact, with an estimated cost to the UK economy of £24 billion per year°. The cost to the NHS alone is estimated to be in the region of £4.3 billion per annum for diagnosis and treatment¹¹.

Healthcare professionals across various disciplines, have a shared responsibility to ensure that the care and treatment they provide is accessible to all service users, regardless of diagnosis, and to research and apply best practice which is centred around individual needs and capabilities<sup>3</sup>.

At a time of fiscal austerity in the NHS and elsewhere, service providers are presented with an opportunity

to seek-out low-cost, low-impact care and treatment options in the interests of both service quality and the patient experience.

The therapeutic use of play and play-based coping strategies has been deployed in paediatric healthcare since the post-war years<sup>12</sup> and healthcare play specialism is a recognised professional specialty in the care of children and young people<sup>13</sup>. Increasingly, it is being recognised that 'play' and play-based interventions also have a valuable role in adult health provision, with a growing evidence base for the protective and restorative benefits of play for health across the lifespan<sup>14</sup>.

The terms 'play' and 'healthcare' are not natural bedfellows in the adult context, and the concepts underlying a play-based approach require elucidation if they are not to be dismissed as trivial or irrelevant<sup>14</sup>. Play has been usefully defined as an activity which generates both immediate pleasure and personal involvement<sup>15</sup> and it is the co-existence of involvement and pleasure that both motivates and focuses the engagement of the participant. In the healthcare context, where patient engagement is key to a successful intervention or treatment outcome, a play-based approach invites the health professional to explore their own creativity and inventiveness in designing services that are efficient, effective and which have the patient at their heart. This process of experimentation and exploration does not demand the acquisition of a whole new skill-set or body of knowledge: the capacity to play is a universal trait<sup>14</sup>. Playfulness, as a therapeutic strategy, is not proposed as an alternative to existing approaches but as integral to the way in which the health professional relates to, and communicates with, their patient. The difference between play and other tools in the professional toolkit is that it is more than just a cognitive activity; play can circumvent the thinking process - using feelings and behaviours as routes to mutual understanding.

#### THE IMPORTANCE OF RELATIONSHIPS

The patient-professional relationship is central to any healthcare involvement<sup>16</sup>, but for patients with dementia and their carers, this relationship needs to go 'beyond what is normally anticipated in imaging and radiotherapy'. The National Institute for Health and Care Excellence (NICE)<sup>17</sup> states that, 'establishing trusting, empathetic and reliable relationships with competent

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and insightful healthcare professionals is key to patients receiving effective, appropriate care'. Generally, relationship continuity is highly valued by both patients and healthcare professionals, and the evidence indicates that it leads to more satisfied patients and staff, reduced costs and better health outcomes<sup>18</sup>.

A positive patient-professional relationship which lends itself to a playful approach, derives from a recognition that the patient is firstly a person with a unique and valuable identity, and from a willingness to get to know the person behind the dementia diagnosis. Time spent getting to know a patient (and their carer<sup>19</sup>) is a judicious investment and can save time which might otherwise be lost to misunderstanding or non-cooperation. In the time-pressured environment of a busy clinical imaging department, where patient contact is more transient in nature, there may be a need to extend usual time allocations. However, a more positive outcome, in terms of more successful interventions and examinations<sup>1</sup>, suggests that additional time spent may be beneficial to patient and radiographer alike.

Familiarisation with the patient and their personal story can help the professional to make sense of otherwise seemingly random behaviours or personality traits, whilst fostering a more meaningful interpersonal relationship. This suggests an important role for the carer or family member as advocate for the patient<sup>3</sup>, where care planning requires the integration of a course of treatment into the patient's daily routine<sup>1</sup>, in the context of either imaging or radiotherapy practice. However, it is also noted, that the patient themselves should be fully involved in the decision making process, where appropriate<sup>1</sup>.

Patient 'passports'<sup>1,20</sup>, or profiles which travel with the patient, ensure continuity of care and avert the tedious task of having to repeat basic information at each healthcare encounter. An authentic relationship demands a willingness on the part of the health professional to also share something of themselves, both demonstrating the mutuality of the relationship and providing an aide memoire for future interactions. Linking a name and professional title to a personal characteristic ('I like cats' or 'I'm the one with the curly hair') reveals the person behind the uniform and generates a feeling of mutual warmth which is conducive to playful engagement.



▲ Figure 1: A Traffic Light coping keyring card set (image courtesy of Stickman Communications)<sup>28</sup>.



▲ Figure 2: An NHS Dementia ward (image courtesy of Boex 33)

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#### COMMUNICATION AS A MEANS OF CONNECTION

Staff awareness of the communication challenges faced by those with dementia, is an essential precursor to the provision of services that are supportive of, and responsive to, individual differences<sup>21</sup>.

People with dementia often experience difficulties with verbal communication – for example, problems with finding the right word or following a conversation. The ability to communicate may also be affected by other factors such as pain, the side effects of medication, co-morbidities or sensory impairments<sup>22</sup>.

However, the demise and ultimately complete loss of speech-based communication does not mean that they have also lost the desire or the capacity to communicate.

'It is important not to assume that people with Alzheimer's Disease have lost understanding or knowledge. It is too easy to think that they do not know simply because they do not communicate. We need to take on the challenge of finding ways to communicate successfully, to try different routes to find common ground'<sup>23</sup>.

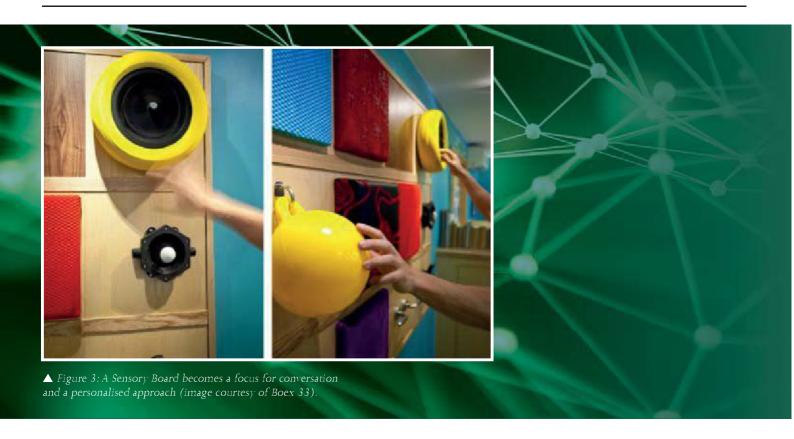
Tom Kitwood<sup>22</sup> explains, 'In the course of dementia, a person will try to use whatever resources he or she still has available. If some of the more sophisticated means of action have dwindled away, it may be necessary to fall back on ways that are more basic, and more deeply learned'

Intensive interaction (Table 1) has been demonstrated as a valuable approach to facilitate respectful and meaningful communication and engagement with individuals with dementia who experience difficulty using spoken language<sup>24</sup>. Intensive interaction is an approach by which the pre-speech fundamentals of communication can be used to engage with another person in a respectful and mutually satisfying way. This approach suggests simple, effective techniques which may be usefully applied by those working in imaging, who need to establish meaningful connections with their patients in a short space of time. Further exploration of intensive interaction techniques would be a valuable CPD pursuit for all radiography personnel.

#### FUNDAMENTALS OF COMMUNICATION<sup>25</sup>

The primary benefit of intensive interaction is that it is a straightforward approach which can be practically applied across settings. It is a playful approach in that it allows for the development of pleasurable and relaxed sequences of interaction, in which the person in the professional role is relaxed and responsive, allowing an activity to flow naturally towards a common outcome. The healthcare context is not given to relaxed and playful interactions and this is possibly the biggest challenge faced by the health professional who wants to explore better ways of connecting with patients with dementia. Feelings of embarrassment, and a fear of being judged or appearing foolish are natural responses to trying something different. Acknowledging

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and sharing our own feelings with trusted colleagues, whilst explaining the change of approach, can be sufficiently empowering to the professional who wants to embrace a playful approach to communication. The emotional satisfaction that arises from making a meaningful connection with another person is in itself self-reinforcing.

It is now widely accepted that most communication is non-verbal<sup>26</sup> and recognising this reduces the perceived disadvantage of those with restricted verbal capacity. At the simplest level, much can be gained by taking a few minutes to observe a patient's behaviour before making an initial approach, and allowing oneself to absorb the possible meaning behind the patient's vocalisations, movements, gestures and attentional focus<sup>26</sup>. The sensitive professional will then be ready to accept what the patient offers to an interaction, and to receive and accept what is being communicated, rather than attempting to deny or dismiss unusual or seemingly random behaviours. Such observation, listening and acceptance are perhaps more helpful when working with the patient with dementia, than the verbal approach more typical of healthcare interactions. A smile or handshake, coupled with positive attention, is less challenging to the patient with dementia than direct questioning – although the patient should also be included in spoken conversations. A diagnosis of dementia is frequently accompanied by a loss of self-esteem and heightened anxiety about getting things wrong; even seemingly innocuous enquiries (regarding the weather, for example, or a patient's journey to the hospital) can trigger anxiety about giving a 'wrong' answer.

"I worry about making mistakes and don't participate in activities. Life used to be so easy, now I have to think hard about everything"  $^{27}$ .

Positive attention in the form of a reassuring phrase or action (a smile, a nod, or other gesture to signal 'here we go, everything's fine') can be repeated throughout an interaction, or sequence of interactions,

to indicate acceptance and positive progress.

A willingness to be playful, including the use of humour, can help to alleviate the tensions inherent in a healthcare interaction, although sensitivity to each individual's temperament and communication style will determine the appropriate timing and focus of a light-hearted intervention. Sometimes the practitioner just needs to trust their intuition, to go with what feels right at the time. The use of humour can feel risky and may seem contrary to the sober ethos of a typically 'rule-dominated' workplace, but humour is something that we incorporate in many of our personal interactions and, applied benevolently and with good intention, can be a worthy experiment in creativity. An innovative application of this concept, particularly for those whose capacity for verbal communication is diminished, is the use of 'mix and match' cards that patients can show to practitioners to demonstrate how they feel. Stickman Communications enables individuals to create a 'personalised pack of cartoon communication cards to brighten up our day, explain without offending, and get the message across with humour'28. For example, Figure 1 (page 19) features a traffic light coping keyring card system, which can easily convey if the patient is coping with the current situation (I'm okay with this), or may need additional support (this is a bit much) or intervention is required (I can't cope with this)28.

As Dean suggests: 'Humour ... has considerable merit in providing a means of access to otherwise inaccessible territory. As well, its power to transform the moment is too vital to be ignored' <sup>29</sup>.

#### THE ROLE OF THE ENVIRONMENT

According to Bandura's theory of reciprocal determinism<sup>30</sup>, our thinking, behaviour and the environment are constantly interacting and changing the way we think and feel. What, how and where we do things are linked together and each will affect the other. This highlights the need to consider environmental factors when engaging with people who have dementia



and suggested environmental adaptations for both imaging and radiotherapy environments are detailed within the clinical practice guideline.

An imaging or radiotherapy department can be a frightening place for any patient but for patients with dementia, the bright lighting, noise, complex machinery and a surplus of printed material, can represent an overload of sensory stimulation, which may adversely affect the outcome of the imaging or treatment procedure. Many of these features can be modified to prepare an environment that is 'calm and well organised' prior to the patient's arrival and such environmental adaptation is particularly beneficial for patients with dementia. For example, calming music and the use of 'sight-visual way-finding cues and lighting' can help reduce anxiety and enhance cooperation.

Tactile stimulation is particularly effective as a calming mechanism for people with dementia and its use is also advocated in the clinical practice guideline. Agitated patients may need to move around or have something to occupy their hands; adapting the clinical environment to accommodate this, as far as is reasonably practicable, will serve to both reduce anxiety and distress and facilitate patient cooperation.

Anything individuals can touch, feel or manipulate with their hands helps to fill the void left by a loss of language<sup>31</sup>. It is actually the brain that 'feels', so tactile stimulation can have both a stimulating and calming effect on the brain31. Active tactile stimulation can include anything that can be touched and items linked to reminiscence or nature are known to be particularly effective31. For example, virtual environments can be created by using natural resources such as sand, shells or dried seaweed that can be put into a box for a walk on the beach, or using bark, leaves, pine cones and acorns for a walk through the forest. Health and safety restrictions and infection control measures in the healthcare setting challenge the creativity of radiography personnel to find acceptable and appropriate tactile resources, suited to their own clinical space. The simple introduction of a 'fiddle box' or 'fun tub'32 that contains tactile objects of different shape, size and texture, such as sorting buttons or textures1 can transform a waiting space in a matter of minutes<sup>31</sup>.

The environment itself, through the use of shape, form, colour and light, can serve to positively contribute to the healing process<sup>33</sup>.

This relatively simple concept can be replicated within an imaging or radiotherapy department, with objects or music that are significant to the patient being used to personalise their experience within the imaging or radiotherapy setting. The sensory board can also provide a means of distraction and embody the experience for the patient, localising them within the treatment or intervention journey. Props and comfort objects such as a soft toy or photograph, can be particularly useful when repeat visits are required. Here again, the role of the carer is crucial in the selection of appropriate distraction or comfort materials, in the interests of best practice for dementia care<sup>21,35</sup>.

Walsall Healthcare NHS Trust Radiology Services have adapted an inpatient room by decorating it with a wall vinyl featuring a forest environment and a band-stand. The wall vinyl features a number of hidden insects and animals between the trees, providing distraction for more apprehensive patients, 'in line with the Trust's dementia friendly policies'<sup>34</sup>.

Boex (figures 2 and 3) uses a participatory approach when designing projects, engaging with patients, staff and carers as a formative part of the design process, as

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evident in a recently completed dementia ward<sup>33</sup>. Playful features that aid conversation and reminiscence, have become integral features of the ward environment, as well as images of the local environment that serve as localising points for the patients. A sensory board has become a central focal point on the ward and 'enables stimulation for patients and provokes interaction with staff and family. The board features inter-changeable panels that can be updated dependent on the patient's background'<sup>33</sup>.

#### **POSITIVE STRATEGIES TO REDUCE DISTRESS**

There are a number of play-based activities and resources which can be introduced into the radiography context to facilitate the clinical intervention, whilst also improving the experience for the patient with dementia. The choice of activity will depend on the health practitioner's own observations, as well as on information supplied by the carer, in order that any play-based approach may be personalised in support of a positive patient experience.

Commercially available activity aprons and waistcoats with buttons, bows and different types of fabric, enable sensory exploration and are also good for keeping hands busy and conversation flowing. Sensory 'fiddle muffs' <sup>32</sup> serve a similar purpose and a voluntary or charitable organisation might be engaged to sew these by hand for a minimal outlay.

It is important that patients are allowed to initiate any exploration of distraction materials and that sensory resources are introduced in a respectful and unthreatening manner – most helpfully under the guidance of the carer or family member.

Carers may also be engaged with the idea of using a 'transitional object' to ease transfer to the unfamiliar hospital or clinic environment. Whilst traditionally recognised as a comforter for young children, a transitional object such as a shawl or cushion or other familiar object can also provide patients with dementia with a comforting link to the home environment<sup>36</sup>.

Pictorial timetables for both imaging and radiotherapy can help to contextualise imaging procedures or radiotherapy treatment. Skinner identified that breaking information down into 'bite sized chunks' when preparing children to undergo a complex procedure may help them to turn the procedure into a manageable task — and the same applies to adults<sup>30</sup>. This can be done in a visual form, as an alternative method of communication, especially for schedules or routine. The following website offers free resources to assist with the creation of pictorial communication systems: http://do2learn.com/picturecards/VisualSchedules/index.htm

Story boards are another form of graphic representation that can be used to provide the user with a detailed overview of a project (or in the case of radiotherapy, a treatment journey). Similar to the preparation books used with children and young people, story boards for patients with dementia need to be personalised to the individual, where possible, including images of the patient at each point of the treatment routine to embody the experience in time and space. This is a positive strategy that is already being partially used in the Sussex Cancer Centre.

#### CONCLUSION

Using play as a strategy for working with people with dementia (or other patient groups) challenges the expectation that healthcare encounters are typically managed at a verbal – and usually serious – level.

It always takes courage and determination to try something new, to deviate from the status quo, but playful communication is at the vanguard of developing services that are both effective from a clinical perspective whilst at the same time respectful of individual humanity. Some people may worry that using play in elderly healthcare risks infantilising the patient with dementia or undermining their self-respect. However, an acceptance that play and playfulness are fundamental to the human condition, 'highlights the humanity that lies within all of us, at any stage of life ... [and] reinforces, rather than diminishes, the importance of respect and dignity within all human interactions'<sup>37</sup>.

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#### REFERENCES

http://www.sor.org//learning/librarypublications/itp

This article has been prepared following local guidance relating to the use of patient data and medical images.

To comment on this article, please write to editorial@itpmagazine.co.uk



#### **HOW TO USE THIS ARTICLE FOR CPD**

Access a copy of Caring for People with Dementia: a clinical practice guideline for the radiography workforce (imaging and radiotherapy) and review 'Section 7 – Guideline Recommendations'. Explore how your department addresses the recommendations and whether any changes may be needed. For example:

- 1.• Look at the environment within your setting and identify ways to minimise excessive sensory experiences
- 2. Identify ways to involve family members and/or carers to assist you when they accompany a patient with dementia.
- 3. Explore how you can apply the use of 'tactile stimulation' to provide relaxation and distraction benefits for patients with dementia.

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