

Acknowledgements

The materials in this resource guide have been compiled following workshops at Northumbria University and the Church of the Holy Nativity in 2013.

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North East Dementia Alliance

Northern Rock Foundation

All the contributors to the workshop events



About this Resource Guide

North East Dementia Alliance

The North East Dementia Alliance is a partnership of health, social care, voluntary and private sector organisations. They work to drive up improvements in health and care, create dementia friendly communities and improve research.

In February 2013 Northumbria University made an application to the North East Dementia Alliance to host a workshop and produce a resource guide to help raise awareness of the spiritual needs of people with dementia. In particular Northumbria University aimed to explore how local communities could be more involved in meeting the needs of people with dementia to be supported to maintain their spirituality.

This project uncovered a range of valuable information including guides, websites and film clips which have now been brought together in this publication. We hope that this will be useful to signpost people to materials to raise awareness and help take this forward at a local level.

The case studies featured in this publication provide examples of how individuals and communities in our region have made a significant impact in supporting people with dementia and their carers. We hope that other communities may be inspired to consider what could be done to improve local support. We are aware that there will be other initiatives that we may not have captured; however we hope that some of the information in this guide may be useful to individuals, community groups and organisations to demonstrate some existing approaches to meeting the spiritual needs of people with dementia.

Northumbria University Workshop April 2013

Resources shared in the delegate packs at the workshop:

Spiritual Care and People with Dementia Click here to download a copy

Visiting People With Dementia Click here to download a copy

Worship and People with Dementia Click here to download a copy

SIMHNE Leaflet Click here to download a copy

Stirling University Leaflet Click here to download a copy

Summary report of this workshop Click here to download the summary report

Dementia Friendly Communities

The term 'dementia friendly communities' reflects a growing movement to remind society that people with dementia have the same rights as everyone else to be treated with dignity and respect, to lead independent, autonomous lives and to continue to be active citizens in society.

This portrays a community that most people take for granted but from which people with physical, sensory or cognitive impairments often become excluded through physical, social, psychological and/or economic barriers.

The quest for dementia friendly communities recently received a boost from the Prime Minister's Challenge on dementia, launched alongside Alzheimer's Society's Dementia 2012: a national challenge.

Many people are excluded from communities and the support they can receive from their communities.

See report on Community Connectedness here

Knowing the Foundations of Dementia Friendly Communities for the North East

This report was commissioned by the North East Dementia Alliance to inform their programme of work on dementia friendly communities for 2012-2013. It outlines some of the building blocks for a dementia friendly community and identifies useful resources.

Download Dementia Friendly Communities final report here

Joining the Dots

'Joining the Dots' were two half-day conferences which brought together people from across the North East to discuss how we develop dementia friendly communities right across our region

Download the Joining the Dots Newsletter here

Minority Communities and Dementia

To find out more about support and care for people from minority communities living with dementia, click here to see the report produced by the North East Dementia Alliance.

Spirituality and Dementia Friendly Communities

Evidence highlights that an important strength of faith communities lies in their interconnected relationships across generations that are developed over time. These social connections help people find meaning, hope and nurture and are well documented as promoting mental health. Faith communities often have deep roots in local communities, embedded in a way that few – if any – other organisations are.

There is considerable research that links spirituality to health and wellbeing. It is important therefore to maintain an individual's spiritual requirement and endeavour to help individuals to maintain important connections. We need to be aware of the need to include spiritual assessment as part of the holistic assessment of any individual who may access our services.

Many older people are socially isolated and even if they do have family members, they may not be closely involved. When people can no longer attend activities that have previously been important to them this can contribute to further isolation and lead to depression.

Although most people with dementia live in their own home, many individuals at some point may move into a care home. This may be in another locality away from their local community.

More consideration needs to be given as to how an individual can be supported to maintain links with their spirituality.

Church of The Holy Nativity Community Initiatives

The Church of the Holy Nativity in Chapel House Newcastle is close to a community shopping centre and health centre. They used funding from the Ballinger Trust, SITA and Big lottery fund to build community facilities including a Peace Garden. The design is dementia friendly and the project was supported by local schools and community groups. For more information click here. The image can be found on the front cover of this document.

Care ConneXion Café – a wellbeing café for people who live with memory difficulties, carers and former carers. This is held monthly at The Church of the Holy Nativity Newcastle which is close to a neighbourhood shopping centre and Health Centre. There is partnership and engagement with Newcastle Carer's Centre, Red Cross, PALS, Dementia Care and other organisations. The cafe offers a light lunch, conversation, social and gentle recreational activities, individual therapies, helpful information and personal advice on budgets and resources available in the area.

The church holds a range of informal religous services for people with dementia and uses pictures and objects to stimulate participation eg knitted nativity figures.

Maintaining connections with communities and familiar spiritual practices can greatly benefit the wellbeing of this vulnerable group of people. It can also help staff and individuals who come into contact with people with dementia to develop a more positive attitude and understanding of the individuals as people within a community with a history and continuity. Retaining continuity and stable social relationships is part of the recipe for successful ageing.

Spiritual care has been defined as: 'That care which recognises and responds to the needs of the human spirit when faced with trauma, ill health or sadness and can include the need for meaning, for self worth, to express oneself, for faith support, perhaps for rites or prayer or sacrament, or simply for a sensitive listener. Spiritual care begins with encouraging human contact in compassionate relationship, and moves in whatever direction needs require.' (Spiritual care matters, NHS Education for Scotland 2009)

NHS Education for Scotland. Spiritual care matters (2009)

Tees, Esk and Wear Valleys NHS Foundation Trust Spirituality Flower:

The TEWV Spirituality Flower has been devised by trust staff and service users working together. It aims to promote a wider understanding of what spirituality might mean for people using the trust's services and is being developed as a tool for identifying what spiritual or religious needs or concerns they might have.

In services where the flower has been piloted, it has been displayed prominently on wards and units as an indication that this is a subject which can and should be talked about when relevant. Service users have often been involved in producing the displays, and this has enabled conversation about their own understanding of spirituality and its importance for them.

The flower is also included in patient information packs and there is opportunity for people to discuss it with a member of staff if they wish, whether to highlight immediate spiritual concerns and needs when they are first admitted to a service or to explore the subject area more in more depth later in their treatment. Consideration is also being given to what is needed to make this a meaningful process for people with dementia or learning disabilities.

Information leaflets are available to give further guidance on how to raise and explore the subject of spirituality and on what actions might help to meet somebody's spiritual needs. The Trust's Chaplaincy service is also always on hand to give support to staff and service users in this work.

For more information on this initiative click here

Jewell (2012) identifies that we are all spiritual beings even if we do not claim to be 'religious' and that whatever our age or condition we all have basic needs such as those identified below.

Spirituality is about:

- Hope and strength
- Trust
- Meaning and purpose
- Forgiveness
- Belief and faith in self, others, and for some this includes a belief in a deity/higher power
- Individual values

Our Basic Needs include:

- Love (receiving and giving)
- Belonging (friendships)
- Hope and dreams (something to look for ward to)
- Faith/Trust (something/someone to believe in)
- Peace (a measure of security)
- Creativity (expressing oneself)
- Worship (wonder and thanksgiving)
- Morality

These can all lead to a sense of fulfilment and the person may experience a sense of calmness, wellbeing or joy that can stay with the person over a period of time, even if they cannot recall the actual activity or experience that led to this feeling.

It is important to acknowledge that a person's spirituality is not static and it changes over time or in response to life events, values and beliefs. People with dementia have the same needs as anyone else but as dementia affects cognitive skills, a person may need assistance with continuing with hobbies, maintaining memories, or preserving a sustained involvement in community life.

Kitwood (1997) advocates that personhood is maintained and that the person with dementia does not lose their sense of identity through loss of autonomy as their memory decreases. Learning about the history of people with dementia can provide crucial insights into their needs. This is important to remember when caring for people with dementia and promoting person centred care.

Communicating with people who have dementia

The following fact sheet has been produced by the Alzheimer's Society and gives helpful tips and advice on communicating with someone with dementia and how to encourage the person to communicate in whichever way works for them.

To download the fact sheet click here

See also the leaflet produced by Stirling University

Communicating with the person with dementia-top tips click here

Talking Mats are a simple, low-technology device specifically developed by speech and language therapists to help people with a range of communication difficulties express their opinions. Talking Mats is an interactive resource that uses three sets of picture communication symbols – topics, options and a visual scale – and a space on which to display them. This can either be a physical, textured mat, or a digital space, for example a tablet, smart board or computer screen.

The enclosed evaluation report gives more information

For more information about talking mats click here



Dementia Friends Initiatives

About Dementia Friends

People with dementia sometimes need a helping hand to go about their daily lives and feel included in their local community. Dementia Friends is giving people an understanding of dementia and the small things they can do that can make a difference to people living with dementia - from helping someone find the right bus to spreading the word about dementia.

The aim is to create a network of a million Dementia Friends across England by 2015.

You can get involved in two ways: become a Dementia Friends Champion or become a Dementia Friend.

This is one way your community organisation can improve their understanding of the needs of people with dementia. For further information click on the link below

http://www.dementiafriends.org.uk/

If you are interested in attending any training in your local region or finding out who your local dementia champions are contact the regional representitive on the Dementia Friends website.

Providing services/ opportunities for worship for people with dementia

Maintaining spiritual practice for people with dementia is often overlooked by communities, care providers and faith organisations. So many things are lost when someone has dementia. If they have previously been part of a faith community they often find some comfort in having some form of contact or recognise familiar aspects such as music, prayer or objects associated with practice of their spirituality. When holding services for people with dementia, visual displays are useful as well as some familiar objects related to their faith practice. Music and prayers should be brief and traditional.

More advice is available in the MHA Publication Worship and Dementia

Northumbria Healthcare NHS Foundation Trust Chaplaincy team have

been working with their colleagues in Speech and Language Therapy to produce some pictures and prompts for people who may have difficulty in participating in services due to cognitive impairment or language impairment. The use of images such as praying hands can help indicate that a prayer service is available. There is also a project underway to make a sensory quilt with a range of textures and materials. This will be useful when with people with dementia to encourage discussion or interaction, as well as being a shared, inclusive initiative.

Research from Staffordshire University identifies that faith communities have a useful role in helping to change attitudes to dementia. They are also well place to recognise changes in behaviour and provide support to individuals and carers. Download Staffordshire University presentation here.

Ministry in the Vale of forgetfulness is a project set up in Sheffield to promote services for people with dementia in hospital and care home settings.

Click here for Presentation

Other recommendations from Workshop event at Northumbria University in April 2013

- Allocation of Dementia Friends in faith communities
- Provision of transport
- Dedicated services in care settings and places of worship
- Traditional simplistic versions of prayers and readings
- Improved signage
- Use of images, pictures and objects associated with spirituality to promote discussion
- Use well known hymns and try to have musical input

A research project was carried out locally looking at Christian worship leaders' attitudes and observations of people with dementia. To see the report of these findings click here

Newcastle Upon Tyne Hospitals NHS Foundation Trust

The Chaplaincy team and Palliative Care team worked together to raise awareness of Spirituality across the hospital sites. They arranged a Spirituality Matters awareness campaign including poster and banner displays. They held a series of focus groups with staff and produced a wallet sized leaflet entitled 'Spirituality matters. Helping you help your patients'. The aim of this is to encourage staff to provide the same level of attention towards spiritual needs as they do to physical needs. This leaflet helps explain what spirituality is and how to assess spiritual need. It also highlights the importance of practising spiritual care and the value of 'being with' someone at the point of their deepest need. It considers the importance of attitudes and behaviours. There are some useful questions to help staff to talk about spirituality issues with patients.

They also produced some educational worksheets as part of the Current learning in Palliative Care series and deliver ongoing education with staff to help them identify cues that may indicate spiritual distress and how to respond to them. An automatic referral to chaplaincy occurs when someone is entered onto Care of the Dying Pathway.

The chaplaincy teams also host services and celebrations of key events in long stay older people facilities.

Providing community support for people and carers

In times of limited resources, there has been increasing reliance on community and voluntary groups to help address some of the unmet needs of vulnerable groups in our society. Some of the examples included below have utilised premises from faith groups to set up community activities and support. These are often successful due to the historical engagement with existing communities and recognised inclusiveness, even to members who are not part of the faith community but welcomed to access activities/support offered. The availability of meeting rooms and premises in neighbourhoods and communities can also be a valuable resource for volunteer groups. Also there may be some local people prepared to give some time and skills to provide support.

Circle of Support Group for People with Family Members living with Dementia. This initiative is supported by Ponteland United Reformed Church and Diagonal Alternatives, Ponteland.

Circle of Support Group meets weekly to provide a listening ear for people who are caring for family members with dementia. The wealth of experience brought by group members enables resource sharing for the many questions families face.

This is a group that listens, empathises, laughs and cries, affirming the carer in their lived experience and concerns.

Circle of Support also runs occasional public meetings with invited speakers to enhance community knowledge and understanding of living with dementia.

Diagonal Alternatives also provide an information and advice service for carers based at the Dene Centre Newcastle

Dementia Friendly Environments

The physical environment of homes, buildings and public places can have a significant impact on mobility and orientation of people with dementia. Good lighting and clear signage at eye level can make a positive difference in helping people navigate their surroundings. There is a lot of guidance around signage and environmental design that may be useful for places of worship to ensure there is good lighting and clear signage throughout. Sometimes pictures as well as language on signs for example toilets are most effective.

The environment where people wish to practise their spirituality is important. This extends beyond designated places of worship. It can incorporate indoor and outdoor spaces that allow individuals to have an opportunity to have time to 'escape' from noise and distraction.

The Quiet Garden Movement

Quiet Gardens and Quiet Spaces: A simple ministry of hospitality and prayer

"Come with me by yourselves to a quiet place and get some rest" (Mark 6:31)

The Quiet Garden Movement encourages the provision of a variety of local venues where there is an opportunity to set aside time to rest and to pray. These may be located in:

Private homes and gardens which are open for occasional days of stillness and reflection. For those who visit, these become oases, places of withdrawal and meeting, of spiritual refreshment and support.

Retreat centres or local churches which offer within their premises an area of beauty and peacefulness dedicated to quiet prayer and solitude.

Inner city areas which seek to create places of stillness and beauty amidst the hustle and bustle of life, sometimes in apparently unpromising surroundings. These can become a focus for the local community.

Prisons which can provide a tranquil, green space for both staff and prisoners

North East Organisations involved

Krysan for Wellbeing, Houghton-le-Spring, Tyne & Wear. tasc.mm@btinternet.com

Further information and resources about environment and design can be found on the University of Stirling Dementia Services Development Centre. Design resource centre. Click here to find out more about the Design Resource Centre. They have also produced a Dementia Design Checklist.

Hampshire Council and Innovations in Dementia collated a checklist which highlights the need to look at signage, lighting, flooring and heating with some checklists for organisations and communities to consider.

Outside space is also very important and The Quiet Garden Movement recognises the value of setting up outside space to allow reflection and contemplation.

Department of Health Dementia Self assessment Framework

This is a nationally developed tool to benchmark the implementation of the nursing contribution to dementia care, including the 6Cs and dementia pathway. It is for use by health and social care staff, as well as wider teams and organisations when:

- considering changes to improve practice
- developing a plan
- reviewing progress around their involvement in dementia care across the whole pathway

To access a word copy of this framework just click on the link below

https://www.gov.uk/government/publications/dementia-self-assessment-framework

Assessment of Spirituality

Many people do not see themselves as being spiritual, and may not be aware of their own spiritual needs or the needs of people they come into contact with. One of the simplest ways of determining what holds importance for individuals is to ask them what gives their life meaning. You could even ask what lifts their spirit or what makes them feel happy.

In order to assess staff's views on Spirituality we recommend the use of the Bodek Spiritual Assessment questionnaire exercise. This is quite an extensive assessment but is useful in helping individuals recognise personal spiritual dimensions.

Download the Bodek Questionnaire here

Use of the FICA tool

This is recognised as a useful straightforward tool for staff to use when taking a spiritual history. It covers 4 dimensions:

Faith Importance Community Address in care

Leading to the acronym FICA. This tool fits particularly well with the intent of this resource pack as the community is considered. Remember that spirituality is not static and regular assessment may be required to ascertain beliefs and values which may change over time. Additional support may be required from chaplains or faith leaders. It is important to be aware of your own spiritual beliefs and not to impose these on others.

Download the FICA TOOL

Further information about FICA from The Hartford Institute for Geriatric Nursing

The "Belief In Recovery project" was implemented by Northumberland Tyne and Wear NHS Foundation Trust in response to patients identifying that spirituality was an important component of recovery in mental health (hope, self identity and meaning) and that services were not as responsive to these needs as they should be.

The aim of the project was to improve understanding of patient's spiritual needs and how as a service we responded to these needs. Two essential components of the project were the employment of Peer Support Workers to utilize their expertise of the role that spirituality played in recovery and the development of a staff training module.

The Peer Support Workers carried out patient focus groups to develop further understanding of spirituality from the patient's perspective and the organisation conducted a staff survey to gain an understanding of their training needs. The information collated informed the development of the training module. Training is delivered in a tripartite partnership between Chaplains, Clinicians and Peer Support Workers and has been highly evaluated by staff.

Practice guidance has been developed including a recommended assessment tool. An assessment of patient's spirituality is now a core assessment.

Peter Ledger, Clinical Nurse Specialist peter.ledger@ntw.nhs.uk

The Reverend Neil Cockling, Chaplaincy Team Leader neil.cockling@ntw.nhs.uk

This initiative has been written up in the Nursing Times and can be accessed here

Use of the HOPE and other assessment tools

Another commonly used tool is The HOPE Questions as a mechanism to assess spiritual care.

- H: Sources of hope, meaning, comfort, strength, peace, love and connection
- O: Organised religion
- P: Personal spirituality and practices
- E: Effects on medical care and end-of-life issues

More about the use of HOPE and FICA in palliative care settings

Another tool recommended is based on the Acronym SPIRIT detailed in the article below

More information on spiritual assessment tools for Chaplains

Some people may be very upset or distressed about an aspect of their spirituality. They may need additional assessment or support from chaplaincy or other services to help address these needs.

More information about assessing spiritual distress

Seeing the PERSON with dementia NOT the person with DEMENTIA

Life Story Work

Excellent care and support is based on building relationships. This involves recognising the uniqueness of the person and their life experiences, which influence not only who they are and how they behave, but also their hopes and wishes for the future. Life story work enables us to see people as individuals in the context of their relationships with others, thus preserving their unique identity and enabling their rights to be respected and valued. By asking carers to assist with constructing a biography of the person before they had dementia, we can gain insight into the person's previous interests which may be useful when planning activities that they may wish to be involved in. http://www.lifestorynetwork.org.uk/

Living well with Lewy Body Dementia

This Blog has been written by Ken Clasper who lives in the North East. Ken offers insight into many aspects of living with dementia, he is especially passionate about the value of maintaining spirituality. Ken was the keynote speaker at BOTH Spirituality workshops and his full speech is on the website as well as comments from readers.

http://ken-kenc2.blogspot.co.uk/2013/05/dementia-and-spiritual-needs-of-those.html

'This is me' resource

'This is me' is a resource produced by the Alzheimer's Society to help care staff better understand the needs of people with dementia. The leaflet provides professionals with information about a person with dementia to help enhance the care and support they receive whilst in an unfamiliar environment. It is not a medical document. Download 'This is me'

This is me provides a 'snapshot' of the person behind the dementia and helps care staff to learn about the person's habits, background, likes and dislikes. This form can be completed by the person with dementia or their carer with help from the person with dementia where possible. This initiative is supported by the Royal College of Nursing (RCN) http://www.rcn.org.uk/development/practice/dementia



Role of the Arts and Creativity

There has been an increasing interest in older people engaging in the arts as part of activity provision in care homes. Engagement of older adults and older adults with dementia in participatory arts can help improve cognitive functioning, communication, self-esteem, enjoyment of life, memory and creative thinking, by providing opportunities for meaningful social contact, friendship and support within the arts groups themselves, as well as improving relationships between care home worker and residents in care homes

Link to Creative Care Homes Document

Familiar art forms such as story telling have also been adapted for people living with dementia. For example, 'TimeSlips' is a creative story telling method developed at the Centre on Age and Community at the University of Wisconsin, Milwaukee. This helps people with dementia to connect with staff, family and friends and encourages them to cultivate their imaginations. Research has shown that the longer people with dementia communicate, the slower they progress into the deepest phases of the disease.

For research examples of the benefits of participating in the arts, for people living with dementia in a wide range of settings please also see: The Baring Foundation report on Ageing Artfully.

This report focuses more broadly on older people and the role of arts in improving health, well being and quality of life.

The report also defines arts and arts related activities, in their widest sense, as well as experiencing arts such as going to shows and exhibitions and having themed cultural events.

Sporting memories – click on the link and play the featured video Bill's Story

http://www.sportingmemoriesnetwork.com/

Northumberland Writer Romi Jones has Experienced Alzheimer's Disease both in her personal and her professional life. Romi is also writer in residence at Castleside day unit part of NHS Northumberland, Tyne and Wear NHS Foundation Trust Dementia Services. She works with groups of residents undertaking writing projects and poetry with residents. Romi has led workshops at Northumbria University to enable staff to gain an understanding of how to engage people with dementia in writing projects. She has also been commissioned by New Writing North/Newcastle University Changing Age as part of The Dementia Writing Project. Here she writes about what the disease can do to older people - and what we can do to make the situation better View this article here Contact: romi@romijones.co.uk

New Writing North has been working in partnership with the Changing Age team at Newcastle University, Alzheimer's Society and Age UK Newcastle to better understand the science and the experience of living with dementia. This project has brought together the arts and literature community with the science community and dementia care specialists to raise public awareness of living with dementia. Further details can be found here. http://www.newwritingnorth.com/text.html?id=dementia

Age UK summary of the benefit of music for people with dementia

http://www.ageuk.org.uk/health-wellbeing/conditions-illnesses/dementia-and-music/

Singing for the Brain is a service provided by Alzheimer's Society which uses singing to bring people together in a friendly and stimulating social environment. Singing is not only an enjoyable activity, it can also provide a way for people with dementia, along with their carers, to express themselves and socialise with others in a fun and supportive group. This includes activities which build on the well-known preserved memory for song and music in the brain. Even when many memories are hard to retrieve, music is especially easy to recall. Many carers also enjoy taking part in this activity. There are many groups set up across the North East. For more information contact the link on The Alzheimer's Society Website.

View NHS Choices film about singing for the brain

The following clip shows the effect on a gentleman who is in a care home who is given an opportunity to listen to his favourite music on an i-pod. This shows that through the power of music he had a tremendous sense of wellbeing and restored his own identity for a period of time.

http://www.youtube.com/watch?v=NKDXuCE7LeQ

Mindful of Music Stockton Arts Centre (ARC)

This initiative is offerered to people with early onset Dementia and their carers in the Stockton area and provides opportunity to enjoy a social and healthy activity with a focus on singing. The sessions are run by Rebecca Pedlow who has worked for over 20 years as a singing teacher, workshop leader, Arts Manager and Project Leader. The project also offers sessions in 6 local care homes throughout the year.

Some highlighted results of the sessions:

- Experience indicates that residents have a better experience when there are higher
- numbers of carers participtaing. However realistically it can be difficult to maintain a high carer/resident ratio.
- Providing lyrics can be a great benefit to some, and extremely confusing to others, so should be assessed carefully in consultation with carers.
- Relevant training of practitioners is essential to ensure quality of delivery.
- Songs that work vary dependant on the ages, tastes and musical ability of individuals in the group. It is essential to assess each group before sessions start, and continually assess song choices as the session progresses. Being empathic to individuals, listening carefully and running with a song of their choice can be key to engaging them in the activity.

An copy of the songbook of lyrics, and reports from the Mindfull of Music project can be emailed on request to rebecca.pedlow@gmail.com

Memory Apps for Dementia is a partnership set up to identify how touch screen technology can benefit individuals with memory difficulties. There is an assumption that you need to be a professional artist or photographer to participate in creating art, but with new technology this is no longer the case. The i-Pad has a range of apps which allow people to create impressive works of art whatever their cognitive abilities using a finger and simple touch controls, from simple painting, music creations, photographic manipulation to interactive entertainment. Newsletters with further information can also be downloaded from this site.

Tees Esk and Wear Valley NHS trust Chaplaincy team

Richard Bradshaw, a chaplain with TEWV, and Alison Watson, of Hand in Hand Care, have worked together in various environments to explore the potential of a range of apps to enhance the quality of life, promote a sense of wellbeing and individuality among people with dementia. The past two years have seen a great surge of interest in using iPads with people who have a diagnosed dementia. Among the pioneers in the field are a team from Worcester University whose website, http://memoryappsfordementia.org.uk/, provides a good introduction. A summary of many of the apps are included in Appendix 1.

Memory Apps websites have been helping to improve the lives of older people living with dementia by introducing them to new touch screen iPad technology. The evaluation by the University of Worcester concluded that access this technology will be an important factor in helping people live well with dementia.

For further details please contact Richard Bradshaw, richard.bradshaw@nhs.net, 01642 837396 or Alison Watson awatson@handinhandcare.co.uk, 0191 500 61 22.

Other Organisations and Resources

Spirituality in Mental Heath North East (SIMHNE) is a regional forum which was set up to further the recommendations of the conference "Making Space for Spirituality" in June 2008 by pursuing issues relating to:

- Education and Training
- Research and Development
- Improving clinical practice... all supported by
- Information and Communication

The Forum membership includes mental health service users, carers, workers, faith community leaders and representatives.

Click here to access the Website and view further information and resources

The Royal College of Psychiatrists have produced a leaflet on Spirituality in Mental Health. This contains a lot of information and resources relevant to many aspects of mental health.

Click here to download a copy

The Leveson Centre

The Leveson Centre was launched in 2001. It arose from a conviction that the contribution of older people, who can inform and enrich the lives of others, was not fully valued. It brings together for study, reflection and exchange of ideas for those of every faith – and none. It publishes a range of useful books and resources, including papers from Leveson Conferences.

Website: www.leveson.org.uk

North East Regional Faith Network (NERFN) is a forum for faith communities across the region which ensures that the voices of faith are heard by local and regional policy and decision-making bodies.

The North East Regional Faiths Network promotes good relations between people of different faiths in the region. Our aims are to bring together people and organisations from all faiths in the region in a network for sharing information, learning from one another, developing skills and projects, and forming partnerships.

Click here to view the NERFN Website.

The following report was produced as part of a collaborative project with North East Regional Faith Network, Churches' Regional Commission in the North East, Vincentians in Partnership, St Cuthbert's Hospice and Public Health North East. 'How Faiths and beliefs help us understand Death and dying'. To see this report click here.

Christian Council on Ageing has a dedicated Dementia Network with leadership from eminent experts within this specialised field.

They share a common concern that people with dementia sometimes are being regarded as persons without the same rights and spiritual needs as any other person and seek to promote a person-centred approach to the care of people with dementia. You can also view a wide range of resources and register to receive a twice yearly newsletter. To find out more about the CCoA Dementia Network click here.

Faith in Older People (FiOP)

This organisation was set up in Scotland and aims to promote a better understanding of the spiritual dimension for older people, complementing the physical, mental and social elements in the delivery of quality person centred care. FiOP work in partnership with a range of organisations in order to:

- Educate, encourage and support volunteers, health and social care workers, members of faith
 communities and other agencies to increase their understanding of spiritual care and issues
 around ageing.
- Deliver events, courses and materials to meet identified need.
- Continue to build the capacity and efficiency of the organisation.

Faith in Older People's work enables people to become more attuned to the spiritual values of compassion, wisdom, truth, beauty, kindness and courage. Link to FiOP Website

A self assessment survey has been designed to examine some important determinants of Faith communities in providing care of older people. This considers the provision of activities and services that may benefit older people in your community.

To see this questionnaire click here

Caritas Social Action Network (CSCAN) is the social action arm of the Roman Catholic Church in England and Wales they have produced a range of information and resources. There is an older persons section on the CSCAN website which recognises the need to address the spiritual and social needs of older people. Members work so that everyone feels included in the community and to feel safe and valued whether at home or in supported accommodation.

The following short film clips consider some important issues when considering the spiritual needs of someone with dementia. Many of these messages are relevant to wider communities.

- 1. It's still me Lord: Exploring Spirituality and Dementia
- 2. The effects of dementia
- 3. Understanding and assessing spiritual needs
- 4. Meeting spiritual needs in care settings
- 5. The Welcoming Parish

These film clips can be accessed <u>here</u>

There is also a resource that can be used with groups of people to accompany these videos this has a range of questions and information to consider next steps in meeting the needs of individuals with dementia.

http://www.csan.org.uk/wp-content/uploads/2012/05/caritas_learning_resource_vs2_.pdf

The Pastoral Care Project raises awareness, develops resources and shares experience to help one another be 'pastoral companions' to frail older people. Their mission is to raise awareness of the spiritual needs of older people. They have established 'Pastoral Companions' in a range of parishes and care homes. They have also been involved in disseminating a range of videos produced by The Catholic Church in England and Wales to improve the understanding of spiritual needs of people with dementia and a video about being a welcoming parish. There are a range of other film clips aimed at promoting understanding of dementia and the effects of dementia. To view these click here.

NHS Education for Scotland produced an introductory resource for healthcare staff called Spiritual care matters. To view this document click here.

Livability is a Christian charity which aims to give disabled and disadvantaged people real choice about how they live their lives .

http://www.livability.org.uk/

Livability has partnered with a new organisation, Passionate Dementia Care, to encourage churches to welcome people with dementia. - See more at:

http://www.livability.org.uk/church/dementia-friendly-churches/

RCN Resources

Although written for nurses, these contain information that may be of interest to anyone with a caring or pastoral role. Spirituality in Nursing care on-line resource identifies the following

Practising spiritual care RCN (2011)

- The practice of spiritual care is about meeting people at the point of deepest need.
- It is about not just 'doing to' but 'being with' them.
- It is about attitudes, behaviours and personal qualities i.e. how we are with people.
- t is about treating spiritual needs with the same level of attention as physical needs.

http://www.rcn.org.uk/development/practice/spirituality

Spirituality in nursing care: a pocket guide. To download a copy please use the following link http://www.rcn.org.uk/__data/assets/pdf_file/0008/372995/003887.pdf

To order hard copies of the spirituality pocket guide, please call RCN on 0345 772 6100 and select option four

RCN Spirituality Survey. A report by the Royal College of Nursing on members' views on spirituality and spiritual care in nursing practice:

A copy can be downloaded <u>here</u>

North East Humanists is the largest organisation representing the non-religious in the North East. We campaign for a more humanist and secular society which is caring, open, rational and just. http://www.northeast-humanists.org.uk/

Film and DVD Resources

Naomi Feil and Gladys Wilson

Naomi Feil, founder of Validation Therapy, shares a breakthrough moment of communication with Gladys Wilson; a woman who was diagnosed with Alzheimer's in 2000 and is unable to communicate verbally. This is the very powerful and moving clip presented at the conference at Northumbria University in April 2013.

http://www.youtube.com/watch?v=CrZXz10FcVM

'Embracing Difference: Dementia Care for Minority Communities' which builds on the play Swags & Tails which was part funded by the North East Dementia Alliance. The DVD was created in collaboration with women, carers and care staff throughout the North East. Whether you are a community group, care provider, a carer, a health or social care professional, living with dementia or keen to know more, this DVD can help you to think through some of the issues surrounding people living with dementia from minority communities. The DVD is free to organisations in the North East if you contact the North East Dementia Alliance at NEDA@newcastle.ac.uk

To see an extract click the link below.

http://www.nr-foundation.org.uk/resources/dementia-reports/north-east-dementia-alliance/

An insider's perspective on what you can do to help a person with dementia - with Christine Bryden

The following clip offers a personal perspective of living with dementia and provides useful insight into some of the challenges encountered and what you can do to help.

http://www.youtube.com/watch?v=7E49cK17qs0

The wellbeing of people with dementia. An initiative from De Montfort University training speech and language therapy

http://www.youtube.com/watch?v=fHni15Bt654

Pastoral Care Project Resources videos

- 1. A prayer for dementia
- 2. My grandparents

http://www.pastoralcareproject.org.uk/videos.asp

Spiritual Care for People with Dementia: Practical Tips

Nursing Consultant Lori Amdam covers some practical strategies designed to encourage both professional and family care givers in the provision of "spiritual support" to older adults unable to verbalize spiritual distress or need. She makes the valid point that spiritual care is often overlooked in healthcare.

http://www.youtube.com/watch?v=ccRx5wRrEBo

Faith in Older People film

http://www.youtube.com/watch?v=YpMcqR9Sh5I

This is a preview of a DVD for staff and relatives to help older people living in care homes realise their spiritual needs. It provides an overview of the spiritual aspects of care.

The DVD also provides case studies that explore the issues discussed from a personal perspective and training tools that can encourage staff to think differently about spiritual care within their care home.

For more information or to order your own copy please contact info@fiop.org.uk

Many examples in Scotland of faith communities are included in the following resource

In Good Faith: Building Compassionate communities

LivingSpirituality is a new group which brings together the contemplative and active dimensions of life, broadly rooted within the Christian tradition.

For more information visit the website www.livingspirit.org.uk

Further Reading

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Appendix 1

Using iPads with dementia clients: a selection of apps

Richard Bradshaw, a chaplain with TEWV, and Alison Watson, of Hand in Hand Care, have worked together in various environments to explore the potential of a range of apps to enhance the quality of life, promote a sense of wellbeing and individuality among people with dementia. We can tell many stories of how working with particular app has awoken a response in service users, and had them concentrating on the screen for extended periods, in a way that no other activity has achieved.

Among those we have found especially successful:

"Talking Friends". These are cartoon characters who repeat whatever is said to them, usually either deeper and slower (Ben the dog) or quicker and higher (Tom the cat). Pierre the parrot is liable to repeat things twice, or get his words scrambled; Larry the bird twitters musically as well as talking. All the characters have other quirks too: Tom will purr if his tummy is tickled, Ben wolfs his food and belches in appreciation, Pierre throws crockery around, Larry is prone to get incinerated by bolts of lightning (but quickly recovers.) Some clients understand that the characters are repeating their own words, others imagine that they are having a real conversation with them.

"Fishpond": the screen becomes a pond. It splashes when touched, which frightens the fish. Lily pads can be moved around, the fish fed, and dragonflies swatted.

"Fireworks": couldn't be simpler. Touch the black screen, you set off a firework. Run your fingers all over it, you get a spectacular display. Doesn't occupy clients for very long but a useful snippet of entertainment to slip in among other apps.

"Pottery": the app begins with a lump of clay spinning on a wheel. The user can shape it into a vase, choose design features, colours and patterns, then put it up for "auction". If there are several patients together in a group, this can become very competitive!

"Swirlicity": against an ambient soundtrack, strands of rainbow colour move around, controlled by the operator's finger. One client, generally unresponsive to the offer of activities, took to this in a big way. It kept her absorbed for quite some time.

"Face Goo" is a warping facility, designed for use with faces that can be manipulated or mutilated into some grotesque caricature, complete with silly hat, glasses or whatever.

"Crazy Face" provides a good range of featureless heads which a client can select, followed by eyes, mouth, nose and a variety of hair-dos, glasses and absurd hats, which can be positioned and sized according to taste. You can also import a photo of a person you know and give them the treatment!

"Flower Garden" – less of garden, more a greenhouse, in which pots of flowers are grown. They need to be watered regularly, and the app will send reminders to make sure you do; so I often start a session by getting someone to help me water my plants. Clients can cut the flowers to make up into a bouquet, which they can then "send" (by email) to friends. They may not have the concept of email but they can still appreciate the visual results.

"ÜberDoodle" - off-putting name for a friendly app which reproduces the old spirograph toy which those of us of a certain age remember from childhood, and allows the creation of spiral pictures in various colours, without the old problem of the drawing pin slipping at the crucial moment!

"Spin art" – does what you'd expect, providing a wide range of templates on which paint can be squirted while the chosen shape is spinning. Suffers from a very narrow choice of colours, but easy to use.

A number of apps provide the possibility of taking spectacularly distorted photographs. Use of these may run into governance issues, but we have the option of taking pictures of ourselves which can then be played with as they are loaded into other apps. With this caveat it is worth mentioning Prank Mirror and Trippy Booth.

A number of apps exist to produce eye candy, often with the facility of capturing it to the camera roll. Tiltoria, Fluidity and – logically enough - Free I-candy are good examples.

Many others offer the experience of generating and manipulating sounds. The very relaxing "Nature Sounds" offers a number of ambient environments ("Bird Garden", "Musical Waterfall" etc.) into which dozens of other sounds can be mixed, from gentle rain to a flute melody.

Another old favourite, "Sound Prism" produces instant "music" at the touch of a finger. The operator can control pitch, timbre and harmonic density of the sounds. Results may be chaotic but rarely dissonant!

Subtler, but one that experience has shown to be very absorbing for clients, even some quite severely impaired, is "Bloom HD" in which Brian Eno has had a hand. Touch the screen to produce a musical note, run fingers over it to generate a sequence of sounds; the app will continue to play these, but through a process of slow metamorphosis which means nothing is every repeated exactly.

Sinesynth is one of a number of apps that produce a riff of up to 16 notes across a 3 octave range. It also offers the potential to modulate and use different scales: several clients have taken to this instinctively and taken great pleasure from the almost instant results it provides.

The daddy of all the sound apps is without question Garage Band. It would be possible, given sufficient musical knowledge, to use its sequencer to produce a six track recording of reasonable quality, so obviously this is not aimed at people with dementia! Yet it has been found to be of great value with clients. As well as letting them "play" strings, guitars, piano and drums, its little sampling facility allows a client's name to be recorded then played back as a sound, up and down the scale – to great amusement.

For more information about dementia-appropriate apps, including others not mentioned here, please contact Richard Bradshaw, richard.bradshaw@nhs.net 01642 837396 or Alison Watson awatson@handinhandcare.co.uk, 0191 500 61 22.