



## John's Campaign



John's Campaign is continuing to gather momentum in Northern Ireland. As noted in previous editions of the newsletter, John's Campaign emphasises the right

of a carer to stay with people with a dementia in hospital and the right of the person with a dementia to have their carer stay with them.

Downe Hospital became the first in Northern Ireland to sign up to John's Campaign and since then further facilities have joined.

St Julian's House in Omagh is the first supported housing association in the UK to sign up to John's Campaign. St Julian's is a joint housing with care and sheltered housing scheme that provides support and care for tenants in their own home. They have open visiting at all times and encourage family to come and stay if they wish, either in the tenant's flat or in their guest room.

Eillis Morris of The Guardian wrote: "We think family are best placed in promoting tenant's rights, as they know their loved one best: their past, their likes and their dislikes."

For further details on St Julian's, Eillis Morris has written a very enlightening and inspiring article

for The Guardian which can be found at [www.theguardian.com/society/2016/jun/03/where-families-make-a-real-difference-to-health-and-wellbeing](http://www.theguardian.com/society/2016/jun/03/where-families-make-a-real-difference-to-health-and-wellbeing)

Holywell Hospital in Antrim have also pledged their commitment to this campaign. In their 50 word application, they said:

**"The multidisciplinary team in Inver 4 Ward at Holywell Hospital pledge their commitment to the 'inclusion of families' and 'partnership in care' when people living with a dementia from our communities become inpatients.**

**This includes daily 'open visiting' and recognising the person's journey, significant others, life biography and importantly maintaining any usual routines."**

It is great to see the momentum building for this very worthwhile initiative but there is still so much potential for growth. Joining John's Campaign is quick and easy to do. All a hospital needs to do to be part of John's Campaign is to welcome carers whenever the patient needs them – 24/7 if necessary. It's that simple. If you welcome carers 24/7 please email [julia-jones@talk21.com](mailto:julia-jones@talk21.com) and say so in 50 words. By endorsing the campaign and lending our support, we hope to raise its profile in Northern Ireland and indeed promote the existing good practice in the region.

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## How can managing medicines be improved?

# Join dementia research

With a high number of people with a dementia living with another medical condition or disability as well as dementia, most will be taking a number of medicines. The COMPARE study, now recruiting through Join Dementia Research, is looking at how managing medicines can be improved for people with a dementia.

We caught up with Dr Heather Barry, Research Fellow at Queen's University Belfast, where the study is being conducted, to find out more.



**Dr Heather Barry**

### **What are the main aims of the COMPARE study?**

People with a dementia may have special requirements in relation to their medicines compared with the rest of the population. This might be due to memory problems and

communication difficulties. The challenges faced by people with a dementia may affect the way in which doctors prescribe and care for these patients. There has been limited research on how medicines are prescribed, reviewed, given and taken in people living with a dementia, particularly for those living alone in their own homes and cared for by GPs and other members of the primary care team. The aim of this study is to improve medicines management for people living with a dementia, by talking to a range of people who may be able to help us do so. We are particularly interested in talking to people with a dementia who are living on their own in their own homes and who are taking four or more medicines.

### **What does it involve for a participant?**

A researcher will arrange to visit the person living with a dementia in their own home to conduct a face-to-face interview about medicines management. During this interview they will be asked a series of questions about their medicines and how they currently manage them, any problems they face, and things that help them with their medicines. Each person will receive £50 for taking part in the study.

### **How long is the study for? Is it a one-off visit?**

People living with a dementia will only be visited (interviewed) once in this study, and the interview usually lasts between 30-60 minutes.

### **What do you hope the outcomes of the study will be?**

In addition to speaking to people living with a dementia, we are also conducting separate interviews with carers, GPs and community pharmacists to obtain their views on how to manage their medicines. We will then combine

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all of this information, in order to develop a plan of how to improve medicines management.

### **Where is the study based?**

The study is based in Northern Ireland and we are recruiting people living with a dementia who live anywhere in the province.

### **Why are you interested in dementia research?**

Seven out of ten people living with a dementia are living with another medical condition or disability as well as dementia, which means that most people living with a dementia will be taking a number of medicines. However we recognise that for people living with a dementia, managing medicines can become increasingly

difficult, and may lead to anxiety for both the person themselves and their family members and carers. In addition, health and social care services need to adapt to meet the needs of individuals. During our research we are particularly interested in how primary healthcare professionals, such as GPs and community pharmacists, can help and support people living with a dementia (and their carers) to ensure they can safely remain living at home for as long as possible.

You can see if you are eligible for this study – and others around the nation – by signing up with Join Dementia Research today at [www.joindementiaresearch.nihr.ac.uk/beginsignup](http://www.joindementiaresearch.nihr.ac.uk/beginsignup)

**Andrea Fisher, National Institute for Health Research**

## **Short breaks and support to carers**

Four new pilot short break programmes will run from the beginning of May 2016 until the end of September 2017. These programmes have been developed and designed with extensive consultation and input from people living with a dementia and their informal caregivers.

This is a very exciting time for the Dementia Together NI project as these programmes will give us an opportunity to help improve the quality of life for people living with a dementia and their informal caregivers.

The findings will also aid in future programme development and the mainstreaming of short break services for people living with a dementia and their informal caregivers.

The short break pilots are:

### **Home support (South Eastern HSCT area)**

This service will be delivered by **Bryson Care**

and available to **30** people living with a dementia and their informal caregivers.

The home support service for people living with a dementia will be primarily delivered within the home and will incorporate either:

- provision of enhanced befriending service including the provision of personal care services to people living with a dementia for a period of 2–4 hours once per week from the time of allocation to the end of the contract period;
- provision of an enhanced befriending service including the provision of personal care services for a period of 2–4 hours and a night sitting service to people living with a dementia once a week from the date of allocation to the end of the contract period;

The logo for Bryson Care features the word "Bryson" in a large, purple, serif font, with a yellow arc above the letter 'y'. Below "Bryson" is the word "Care" in a smaller, purple, sans-serif font. The entire logo is set against a white background within a rounded rectangular frame.

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- provision of a night sitting service including the provision of personal care services to people living with a dementia once a week from the date of allocation to the end of the contract period.

### **Extended domiciliary care (Northern Ireland wide)**

Currently this service is available within four of the five HSCT areas, unfortunately we did not receive a tender submission for the Southern HSCT area. However it is anticipated this will shortly be going back out for tender.

The service will be provided by:

**Homecare NI** (Homecare Independent Living) in the Belfast HSCT

**Homecare NI** (Homecare Independent Living) in the Northern HSCT

**Trackars Ltd** in the South Eastern HSCT

**Hillview Lodge Ltd** (Glen Caring Services) in the Western HSCT.

The purpose of the extended domiciliary care service is to allow the informal caregiver to take a break of up to four days away from the person living with a dementia but may extend to seven days if the formal caregiver is already known and provides services to the person living with a dementia and their informal caregiver.



**Fiona McCann (Dementia Together NI, far right) meets short breaks service providers.**

Extended domiciliary care services will include the provision of personal care for **24 people** living with a dementia in the relevant HSCT area. The overall benefit from this service for an individual service user will not exceed 168 hours (seven days) during the initial contract period.

Services will primarily be provided in the home. However they will also provide for the provision of support services outside the home, (eg shopping, attendance at religious services, other routine social events).

### **Emergency support (NHSCT area)**

This service will be provided by Trackars Ltd. They will deliver an emergency support service for people living with a dementia and their informal care givers in the NHSCT area. The service includes the provision of personal care services between 9am and 5pm for periods of one hour up to eight hours for a maximum of three consecutive days (24 hours in total).

### **Enhanced day opportunities (WHSCT area) to include evening and weekends.**

The enhanced day opportunities service for people living with a dementia and their informal caregiver will be provided by Bryson Care in the WHSCT area for periods from 4 to 6 hours, once a week, for 23 service users. This service will be delivered primarily outside the home environment of the person living with a dementia and should incorporate enhanced befriending including personal care.

As all the short break programmes are pilots, selection criteria have been established to ensure those most in need receive the services. Referrals to each service will be carried out through the person living with a dementia and their informal caregiver's keyworker.

If you wish to find out more about any of the short break pilots please feel free to contact me on 07584422528 or at [Fiona.McCann@hscni.net](mailto:Fiona.McCann@hscni.net)



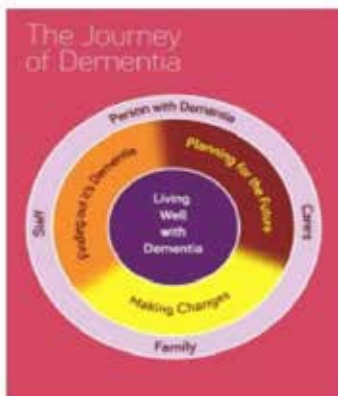
## Training and Development update

### Learning and Development Framework

Following extensive stakeholder involvement and engagement over the last year the Dementia Learning and Development Framework has been finalised and launched in June 2016 in the Long Gallery, Stormont.

Dementia Together NI would like to thank those that engaged with, contributed to and helped to develop this framework, especially those affected by a dementia.

### The Northern Ireland Dementia Learning and Development Framework



*Supporting health and social care staff to deliver better care to people living with a dementia, their families and carers*



### Dementia Champions

The Dementia Champions Training Programme is designed to train 300 existing health and social care staff from both the statutory and independent sectors. Upon completion of the training programme the Dementia Champions will have improved skills, knowledge and understanding of dementia and its impact on individuals. It is envisaged that the trained

Dementia Champions will improve the care experiences of people living with a dementia, their families and carers.

To date over 200 expressions of interest have been received from staff in the statutory and independent sectors to undertake the training.



One cohort in each of the five HSCT areas will commence their training in June 2016, becoming Dementia Champions in December 2016.

### Training of informal caregivers of people living with a dementia

Dementia Together NI has contracted Alzheimer's Society and 3five2to to develop and deliver a training programme for informal caregivers of people living with a dementia across Northern Ireland. Upon completion of the course informal caregivers, family members or friends of people living with a dementia will be better equipped with the knowledge, skills and understanding of caring for a person living with a dementia.

It is hoped that upon completion, informal caregivers will feel empowered, supported and reassured in their caring role as well as being aware of, and knowing how to access, relevant services for their loved ones as they travel through their journey of dementia.

It is anticipated that the first cohort of informal caregivers will commence their training this month.

## General Ward Collaborate Learning Set

The third 'Learning Set' of the General Ward Collaborate took place on 31 May 2016. We had a presentation from SN Sinead Morrow, Ward 2 Lurgan Hospital, in relation to use of 'Distraction and engagement therapies for behaviours of delirium'. She also kindly



loaned some examples of the therapies such as empathy dolls, reminiscence scrapbooks, etc to share

with attendees. They found the presentation and first hand sight of the tools very informative as they could see how they could be used in front line care.

Our second guest speaker was Dr Tammy Angel who attended from Hertfordshire to present her findings of the Delirium Recovery Programme, which consists of discharging medically fit patients with ongoing delirium, to a virtual ward at home.

This multidisciplinary approach and alternative commissioning addressed increased length of stay and risk for patients within the acute setting. The patient was provided with care for 24 hours, seven days per week over a three week period.

The care is reduced as the person's delirium resolves and they are more enabled to carry out their usual tasks. Some patients completed the three week period with no further care requirement, while others were deemed to require more long term care provision within a residential home.

The results showed that there was an increase in improved outcomes for patients, and this alternative commissioning approach saved £206,000 in the first year of pilot with 55 patients. Dr Angel advised that she has been requested to spread the recovery programme across the Trust, and is currently identifying resources etc. to initiate this.



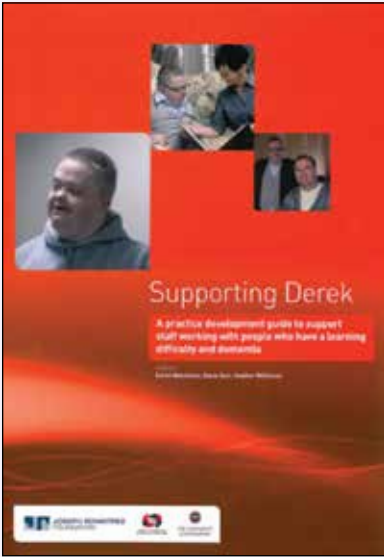
The attendees found that this approach was reflective of their own experiences of the impact of the acute environment on a person diagnosed with delirium. They were able to clarify how certain barriers were overcome in relation to commissioning, protocol for inclusion etc.



## Delirium Awareness Week

Delirium Awareness Week was 14 – 21 June 2016. This is a social media led event that aims to increase awareness of delirium and how services are being improved, reflective of the increased at risk population. This was used to launch the development of regional awareness materials such as patient posters, leaflets and animation. The link to the animation is [https://youtu.be/\\_c9M4FnDwOc](https://youtu.be/_c9M4FnDwOc)

# Learning difficulties and dementia: Supporting Derek



'Supporting Derek' is a practice development guide created to support staff working with people living with a learning disability and a dementia. It is published by the Joseph Rowntree Foundation and was developed in conjunction

with the Centre for Research on Families and Relationships along with key specialists from the University of Edinburgh.

The pack and DVD were produced for use with staff and volunteers who work with people with a learning disability in any setting. The intention is that the pack could be used within a formal training session or more casually to support informal learning, promoting discussion around each of the ten topics included.

The ten topics cover:

- learning difficulties and dementia;
- understanding behaviour;
- developing supportive and meaningful environments;
- responding to pain;

- effective communication;
- meaningful activities;
- when a friend or relative has dementia;
- nutrition and hydration;
- night-time care;
- palliative care.

At the end of each topic there are links to the DVD, activities and suggested further reading. The DVD offers two parts. Part 1 is a short and powerful drama acted by people with a learning disability and their actual support worker. It is designed to provoke thinking and discussion around each of the topic areas in the workbook. Part 2 aims to highlight core issues relating to the support of people with a learning disability with examples of good practice.

Individuals should benefit from watching the DVD, reading the materials, completing the activities and discussing with colleagues or a manager how to apply the learning in practice. The materials are very accessible and offer practical tips that could be immediately implemented.

Each Health and Social Care Trust has 100 copies to distribute. It is hoped that the packs can be used to raise much needed awareness for staff and volunteers providing services throughout Northern Ireland.



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