

FREE | Winter 2013

f Dementia focus



Dementia diaries
Youngsters get writing

Talk about...
Life after diagnosis

Help is at hand

How Kent and Medway are becoming dementia friendly

Welcome

Welcome to the first issue of Dementia Focus, which is a collaboration between the NHS, voluntary organisations and Kent and Medway councils. We want to let you know about the positive changes being made to support people with dementia, their families and carers.

The Dementia Challenge was launched in March 2012 by Prime Minister David Cameron. Kent and Medway successfully bid for £1.5 million from the regional dementia challenge fund to support a number of exciting projects across the county to improve the lives of people affected by dementia.

Projects are focusing on increasing the number of people diagnosed early, improving the patient experience in acute and community hospitals, supporting care homes to deliver improved care, 'dementia friendly communities' initiatives and GP training in dementia awareness.

It is estimated that 22,000 people across Kent and Medway are likely to have dementia, but less than 50 per cent of those people have a formal diagnosis. GPs across the county have recently signed up to a national initiative to invite people for a memory test, as early diagnosis is crucial to getting the right treatment and support to help people maintain their independence for longer.

Amongst other improvements, carers' organisations have received funding to support their important work, which ranges from information and guidance to financial help for carers to respite breaks, and GPs can now refer to these services on a fast-track scheme for those who need urgent support.

I invite you to read on to find out about the hard work that has been happening in our county.

Best Wishes,

Sue Gratton, Associate Partner (Integrated Commissioning) at Kent and Medway Commissioning Support (NHS).

Emma Hanson, Head of Strategic Commissioning (Community Support) at Kent County Council.

Butterfly scheme takes off

Medway NHS Foundation Trust has been working hard to improve the care it offers to patients with dementia, and has launched the national Butterfly Scheme at Medway Maritime Hospital.

The Butterfly Scheme allows people with memory impairment to request specific care during their hospital stay. Opting-in means their condition is symbolised to hospital staff by a discreet butterfly picture on their notes.

Kent Community Health NHS Trust will also be providing the opportunity for patients and their carers to opt-in to the Butterfly Scheme in Kent's 12 community hospitals in the next three months. KCHT's three new dementia nurses will ensure this scheme is consistent in each community hospital.

The scheme provides training for staff to help them tailor their care to people with memory problems. By taking simple steps such as reminding a person living with dementia where they are and why, and explaining what's happening to them clearly, the length of hospital stays for people with dementia can be reduced. The scheme also promotes the importance of family carers and care home staff being able to offer their valuable care insight to those taking over that care in hospital, and allowing the patient to be seen and understood as the unique individual they are.

The nationally-recognised scheme is being introduced to community hospitals across Kent and Medway over the next year, thanks to funding from the government via the Prime Minister's Dementia Challenge.

What to do if you feel unwell

Winter months are the busiest time for the NHS. We see higher numbers of injuries from falls, a surge in illnesses such as norovirus, coughs, colds and flu and the worsening of long-term health conditions, such as respiratory problems.

If you are feeling unwell, please don't delay in contacting your GP practice for an appointment. If it is urgent, the practice will try to see you that day or will arrange for a doctor to phone you back.

You can see any GP at your practice, so if you are feeling unwell don't wait to see "your own" GP. All the GPs will be pleased to see you and can access your notes.

If you feel very unwell or your practice is closed, and you need help quickly, phone 111. NHS 111 is a 24/7 helpline for when it's less urgent than 999.

If you experience chest pains, severe breathing difficulty, serious injury or severe blood loss, or are showing symptoms of stroke, phone 999 immediately.

NHS111 can be reached via textphone by calling 18001 111. A confidential interpreter service is also available in many languages.



Help your community become

dementia friendly

Learn more about dementia

The Alzheimer's Society has published a guide for anyone who has recently been told they have dementia. This could be any type of dementia, such as Alzheimer's disease, vascular dementia or mixed dementia. It will also be useful to close friends and family of someone with dementia, as it contains information for anyone taking on a caring role. The guide is available at www.alzheimers.org.uk/dementiaguide or can be ordered in print.

Organisations in Kent and Medway are calling on people to get involved in Dementia Friendly Communities. Kent and Medway Clinical Commissioning Groups, Kent County Council and Medway Council are setting up 12 dementia friendly communities, and are calling on as many people as possible to get involved.

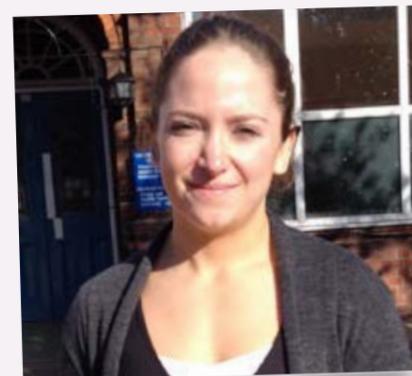
The first 'whole' communities are being set up in Northfleet, Westgate, West Malling, Swanley, Eastry, and Canterbury. Everyone is invited to take part whether an individual, school, business, carer, charity or other community group, to help shape

the dementia friendly community in each area. More areas are being considered for other dementia friendly communities.

To find out how to get involved with your local dementia friendly community, email silk.team@kent.gov.uk or call Margaret Turner on 01622 694639.

There are also other exciting initiatives in Kent and Medway - such as shop safe / stay safe projects in Dartford and Gravesham. To find out more, contact Tracey.Schneider@kent.gov.uk, emma.hanson@kent.gov.uk and peter.marsh@kent.gov.uk

Dementia nurses improve community hospitals



Three dementia support nurses have been recruited by Kent Community Health NHS Trust. Rachel Daykin, Claire Arif and Rebecca Clayton-

Higgins will be assisting the dementia team to develop its services, which began in east Kent with intermediate care teams and dementia awareness training.

The new developments, in line with health commissioners' initiatives, aim to ensure that clients with dementia and their carers experience the highest levels of care in KCHT's 12 community hospitals and other centres.

Claire said: "We will be looking at whether the environment promotes interaction, well-being, encourages eating and drinking, promotes mobility, continence and hygiene. We

will also look at whether or not the care setting is easy to orientate, calm and has adequate security.

"We will be looking at the signs, lighting, flooring and colours to see how they enhance a patient's experience and reduce confusion and anxiety caused by unfamiliar surroundings. Our aim is to identify what needs to be improved in each of the areas while recognising what is working already."

This will be in partnership with existing staff and recognises the good service already being provided in therapy environments.

Managing dementia at home

Medway Community Healthcare runs a support service which helps people with dementia and their families manage symptoms and cope with the challenges of dementia when things are particularly difficult. The team of dementia nurses visit patients and families at home to give support and advice, including coping with communication difficulties and challenging behaviour. The service is for people in Medway in the process of being diagnosed, diagnosed patients and families or carers in difficulty. Referrals to the team can be made by carers, GPs and health professionals on 01634 382947 or at www.medwaycommunityhealthcare.nhs.uk/dementia-support

Home Treatment Services are available across east Kent, provided by Kent and Medway NHS and

Social Care Partnership Trust. They provide enhanced support and treatment for people with dementia and their carers in response to crises and during periods of transition, to prevent unnecessary admission to hospital and to provide support to carers. The teams include mental health nurses, occupational therapists and psychology and support workers.

In west Kent, an outreach geriatrician works with care homes to support people with dementia with the greatest needs. Geriatricians (doctors who specialise in caring for older people) are able to provide urgent assessments and help care home staff with medication reviews and end of life support. This helps people living with dementia to stay in their home setting rather than having to go into hospital.



Own bed is best

In west Kent, Crossroads Care supports patients in hospital to return home as soon as possible. By working with patients, families and healthcare staff, Crossroads co-ordinators identify barriers to patients being discharged and work to overcome them, by providing a range of services both at the time and after discharge, including home visits.

Dementia link practitioners

Dementia link practitioners are now working with GP practices across Kent. Clinical commissioning groups, which now pay and plan for most health services, have arranged for KMPT mental health practitioners to be based aligned with practices, to help assess people who present with memory difficulties. The initiative will ensure people receive a diagnosis in the early stages of dementia and get the appropriate advice and support as the condition progresses.

Excellence in Kent

Support is also available to care homes. Twelve care homes across Kent and Medway have been selected to participate in a training programme to enable them to provide an even better service for people with dementia. In one home, the night staff now wear pyjamas, as it was realised that this had a calming effect over residents who were often very active at night time. The Excellence in Kent scheme offers access to intensive training and involves careful assessment of people with dementia with a system called dementia care mapping. This aims to see life through the eyes of someone with dementia.

APPY DOCTORS

A new memory testing system is being piloted in some GP surgeries across Kent. It uses an iPad app called CANTABmobile to determine whether patients have memory problems, which may be linked to dementia. The app is a clinically researched, NICE approved and evidence based product, which uses anonymous data from 1,000s of patients to compare the tested patient with their peer group. The assessment, which can be done in many languages, takes 10 minutes and enables healthcare staff to detect the earliest signs of memory problems.

Next year, GPs will receive extra support to have conversations with people with dementia, and their families, about the future. By making plans before deterioration, it is easier to ensure that a person's rights and wishes are captured, and respected at the end of life.

Project aims to reduce anti-psychotic medication use



Kent and Medway NHS and Social Care Partnership Trust (KMPT) is running a project which aims to reduce anti-psychotic medicine given to people with complex dementia needs. If successful it could transform the quality of life for hundreds of people in mental health wards and the wider care home community. Based on the Newcastle Behaviours that Challenge model of care, the clinically audited trial is focusing on older people's services in Maidstone.

The Newcastle Model takes account of the biology, the medication, the psychology and the social environment of the person. By combining all those things together to understand the nature of the problematic behaviour, you can then devise a treatment that is less reliant on medication. This promotes wellbeing and reduces distress felt by the person with dementia or learning disabilities, their carers and staff.

Local hospitals are becoming

dementia-friendly



All acute hospitals in Kent and Medway are now screening everyone aged 75 and above, who is admitted as an emergency and spends more than 72 hours in hospital, for any sign of memory problems.

Across Kent, staff are receiving training on cognitive impairment and how to better care for patients who are agitated or confused. They are also focusing on nutritional needs of patients with dementia.

Maidstone and Tunbridge Wells NHS Trust is planning a buddy scheme in partnership with Alzheimer's and Dementia Support Services, which will support specially trained volunteers in spending time with people with dementia whilst they are in hospital.



All wards and both A&E departments provide puzzles and books for dementia patients to ensure they have activities which provide mental stimulation.

Ward 20 at Tunbridge Wells Hospital has a specially designed café area where patients and their relatives have a comfortable area that feels less clinical. This area is utilised for breakfast, lunch and supper and also for activity sessions.

At Darent Valley Hospital patients needing help with eating and drinking are given red meal trays and beaker lids so nurses can easily identify who needs assistance. Windows are left clear so patients can enjoy the view.

Dartford & Gravesham NHS Trust provide a dementia buddy scheme across several wards and A&E at Darent Valley Hospital. The scheme continued following the success of the pilot, which was run in partnership with Alzheimer's and Dementia Support Services and Kent Adult Social Services.

A coordinator manages a group of volunteers who keep patients

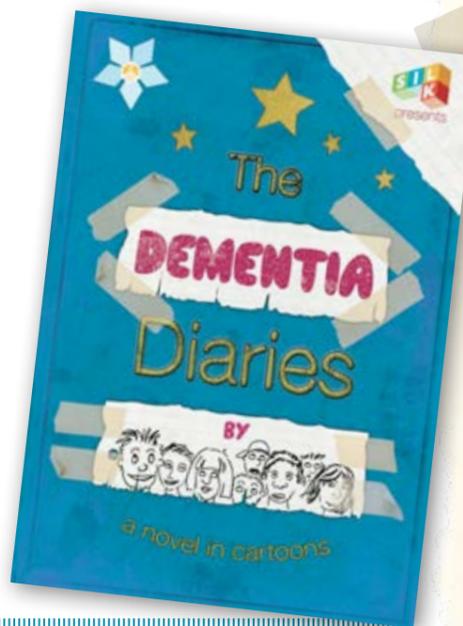
company to prevent isolation. Similar buddy schemes are now in place across the county.

Medway Maritime Hospital is opening an eight bed acute dementia unit with dedicated nurses, and has created memory rooms on older people's wards. These rooms encourage calmness and comfort, but also a place where patients can do activities and have their meals away from the bedside.

East Kent Hospitals University NHS Foundation Trust is piloting initiatives on three wards. It is in the process of personalising bed spaces, introducing large clocks with white boards to help with orientation, and using coloured bays to help patients find their bed areas.

Across Kent and Medway, wards are introducing the Alzheimer's Society's This Is Me information sheet, which enables families and carers of people with dementia to give healthcare staff an insight into the difficulties that person faces. This enables staff to tailor their care even further to the individual's needs.

Diaries are a beacon of hope



Nanny news

Nanny told me she has Dementia today.

And that she's had it for a while. I guess that's why people kept asking me how she was all the time. I would always say she's as silly as ever, and they'd give me a sad look. It was always a bit strange. It's funny because she's always been the same to me. Always full of laughter. She says that's the best way to be! Whatever Dementia is, it's not her.

She's always going to be my nanny. It doesn't change her. And if she loses more brain cells, well, we'll all be there with her doing that together, and if that means we can have a giggle and a boogie on the way too, then I think that's the best thing to do.

Mum's organised it so I can learn to help care for Nanny and go to carers' support groups and meet other kids who have Grandparents with Dementia too. It's like a kind of a family thing really. I even found out that a few of my friends at school had grandparents with Dementia too! Nanny had some good advice, she said, "right, you've got this time now, don't dwell on it, don't take it so seriously and it's not the end of the book, it's just the beginning of the next chapter."

And any book with my Nanny in it sounds like a pretty good book to me!



The Dementia Diaries are a collection of true stories about young people and their experiences with dementia. They are based on touching and funny stories from families across Kent, talking about the good days, the bad days and everything in between.

The stories are told with cartoons and diary extracts by four characters - Brie, Fred, Sam and Sarah. They share their experiences throughout the book as they come to terms with their grandparents' diagnoses.

It has been endorsed by TV presenter and dementia champion Angela Rippon OBE, who has written the foreword.

She said: "The Dementia Diaries are a delight and a revelation. The thoughts of these young people coming to terms with the effect that dementia has on much-loved members of their families are humorous, humbling and overlaid with uncompromising honesty.

"I think it's brilliant to see Brie, Sam, Fred and Sarah representing a dementia-aware generation who will mature into a society in which dementia is understood, dementia patients are respected and the word 'stigma' will no longer be part of the Dementia Dictionary.

"These aren't just diaries – they're a real beacon of hope for the future."

Angela is also a champion for the Alzheimer's Society's dementia friendly communities campaign.

Creators of the book, Kent County Council's Social Innovation Lab Kent, hope the children's accounts of their experiences will prove an accessible way for other young people to understand the nature of dementia. Schools in Kent are already running lessons and projects around dementia and this book will become part of this work.

One of the young people who shared her story, Raisa, said she was happy to be part of something which may help others know they are not alone.

She said: "This book is important; it shows other young people that it's not just them, there are other people going through what they're going through."

The Diaries will be available in libraries, hospitals and every primary and secondary school across Kent. You can also buy copies from Amazon.

Find out more

www.alzheimers.org.uk

Life after diagnosis



Trevor and Julia Seath, who live near the coast in Whitstable, shared their story with Martin from Kent's mental health trust, KMPT.

When the consultant gave the diagnosis, Trevor was remarkably sanguine.

"I didn't have any strong emotion," he said. "Perhaps I should have, when you see what it does to people; it's a horrible thing. My reaction was sort of, ok, I'm just going to have to get on and deal with it, see what comes."

Trevor, 70, was diagnosed with dementia in November, 2012.

Julia said: "We talked about how we felt after the diagnosis. Trevor wasn't terribly fazed whereas I felt isolated and a bit lost, not knowing what to expect and what the journey would hold.

"Some part of it was selfish and another part like grief, thinking will this man that I've loved and married nearly 50 years ago, how long will he be that person?"

"Although most of my friends have been really good, there were some people trying to avoid us if they saw us coming, or changing the subject. It was isolating to feel that people you've known for a long time couldn't cope with it."

Earlier this year, Trevor and Julia attended a Living With Dementia course devised by Kent and Medway NHS and Social Care Partnership Trust (KMPT) for those recently diagnosed and their loved one or carer. It brings together people with various forms of dementia, including Alzheimer's, to share their experiences. They are given clinical knowledge about their condition, the options available and are put in touch with other health professionals, organisations and support groups.

After the initial shock of diagnosis, the couple decided early on to tackle dementia with a positive attitude and good humour.

"We had been watching the TV cookery show, The Great British Bake Off, and I said to Trevor: 'I think I must try to make a Bakewell tart' and Trevor replied 'Oh, yes please, can we have gravy with it.'"

Trevor said: "I knew straight away that I should have said 'custard,' but that's one of the silly things that is getting more frequent. It made us laugh though. She still pulls my leg by saying 'And do you want custard with that?'"

He said that sporadic symptoms include difficulty remembering passages in books, losing the thread mid-conversation and hearing people in larger groups.

Julia revealed why it was important to them to raise awareness about dementia.

"It would be great if people didn't fear it so. It may not be as fearsome and awful as people think."

'It may not be fearsome and awful as people think'

Find out more

www.alzheimers.org.uk

Dementia directory

The NHS in Kent and Medway works in partnership with Kent County Council, Medway council, local councils, charities and voluntary organisations to support people with dementia and their carers.

On the phone

There is a free 24 hour helpline for people with dementia and their carers which offers advice and emotional support – phone **0800 500 3014**.

In person

Dementia cafés

Dementia cafés provide a drop-in service for anyone affected by dementia who may need information or support. You might be a person living with dementia, or a friend or family member of someone who has dementia.

Canterbury and Swale

Age UK Herne Bay, phone 01227 749570

Dartford, Gravesham and Sevenoaks

Alzheimer's & Dementia Support Services, phone 01474 533990

Ashford and Dover

Alzheimer's Society Kent and Medway, phone 08450 405919

Maidstone, Tunbridge Wells and Tonbridge & Malling

Alzheimer's Society Kent and Medway, phone 01892 559410

Medway

The Dementia Café and The Calypso Venue, phone 07557 1110606

Thanet

East Kent Independent Dementia Support, phone 01227 730000

Shepway

Shepway Volunteer Centre, phone 01303 259007

Dementia Peer Support Groups

Dementia Peer Support Groups are small groups for people in the early stages of the illness who have recently been diagnosed.

Sessions are supported by a trained facilitator who will help members of the group to share their experiences of dementia and the impact it has had on their lives. Please note that attendance at the groups is by referral only.

Canterbury and Swale

Age UK Herne Bay, phone 01227 749570

Dartford and Gravesham

Alzheimer's & Dementia Support Services, phone 01474 533990

Ashford, Shepway and Dover

Alzheimer's Society Kent and Medway, phone 08450 405919

Sevenoaks, Maidstone, Tunbridge Wells and Tonbridge & Malling

Alzheimer's Society Kent and Medway, phone 01892 559410

Thanet

Trinity Community Resource Centre, phone 01843 294229

Online

Our Health South East -

www.ourhealth.southeastcoast.nhs.uk

Alzheimer's and Dementia

Support Services - www.alz-dem.org

Mental Health Foundation -

www.mentalhealth.org.uk

NHS services - www.kmpt.nhs.uk/

Dementia-Services

Date for your diary

Kent Dementia Action Alliance Marketplace and Launch

A showcase event and opportunity to network and learn about new services in Kent. Open to anyone with an interest in or affected by dementia.

Date: Thursday 24 April 2014

Venue: Augustine House, Christ Church University, Canterbury