

<u>Older People's Champions update – August 2018</u>

Hi Everyone,

Work to help older people in Ribble Valley continues to provide much needed facilities to stay physically and mentally healthy whilst making friends along the way.

We are still utilising available meeting places, particularly community hubs in our villages, and are continuing to be successful in bidding for, or providing funding or working with care partners to facilitate many of our schemes.

The Older People's Champions Network Northwest still meets every two months and has been focused on the campaign for an Older People's Minister in Government. Whist this has been running for some time, I agreed to lead the campaign last year and wrote to 537 MPs in England for support. We did manage to get a speech in Parliament just before the Easter recess 2018 which was well supported. There is much work still to be done but we are working on it and have made some promising progress.

Ribble Valley Dementia Action Alliance

Along with partners, including the Council, Ribble Valley Dementia Action Alliance has made much progress in providing facilities and respite for people living with Dementia, carers and families.

The Alliance has been successful in bidding for money for further respite care activity and we were so pleased to be chosen by the Mayor Cllr. Stuart Carefoot to share in the Mayor's funds. We have also benefited from the generosity of one of our members who donated the proceeds of an event in memory of his wife. We have promised to put all the money to good use and have some new schemes emerging to support people living with Dementia, carers and families.

We are looking at new venues and different activities in order to provide a more varied offer across Ribble Valley.

The Dementia Action Alliance has gone from strength to strength, we have continued to spread awareness of Dementia across Ribble Valley, the latest awareness sessions being in Whalley at the Old Grammar School and the GP Surgery, Chipping at the Village Hall, Clitheroe at the Council Chambers, Ribblesdale Pool and The Platform Gallery, Wilpshire is next and then Worston.

We have done some respite sessions at The Sanctuary at Old Langho which were successful. Our residents enjoyed the coffee and organic cakes and the fantastic surroundings, also the music. We had a session with the harpist in the Earth Room and had the opportunity to play the Tibetan instruments which our visitors living with dementia, carers and family members found so calming and ethereal. A couple of our DAA members tried the chanting and loved it. We will go back to The Sanctuary later in the year with a view to providing more activities and include exsoldiers from the Admiral Nurse group.

We have been attending the Time for You sessions in West Bradford run by Crossroads, one of our partners and are getting to know the residents there.

We are starting a new project called Souper Wednesdays in September in Langho for people living with dementia, carers and families. It is a lunchtime session once a fortnight with crossroads nurses on hand, soup and roll lunch and various crafts and activities.

Ribble Valley Dementia Action Alliance in partnership with the Council, NHS, care organisations, and people living with dementia, carers and families is taking the lead in responding to the needs of carers and the cared for who are living with dementia in terms of respite care and combatting isolation.

We are working on a 'Singing for the Brain' project and a drumming circle to start in the near future, and also exploring the opportunities for dementia films and plays for our residents.

Our new information booklet is out, I will leave some in the foyer at the Council Chamber.

Following on with the plight of carers, the Older People's Champions Network are looking at the current information from Nuffield Trust in their 'Evidence for better Healthcare' particularly the results of the National carers' survey. It is a fact that whatever the results of the survey are and whatever happens next with social care, informal carers will still play a central role. There are many people who do not recognise themselves as carers, they do what they do every day caring for people because they love them. Families care for family members, friends and neighbours care for friends and neighbours and we need to recognise them and support them more.

It is undeniable that the value of the care provided by informal carers is huge. It is frequently forgotten or taken for granted that the majority of care provided doesn't come from the NHS or care homes, but in the form of unpaid care which is estimated to be worth $\pounds132$ billion a year.

Reliance on informal carers is increasing because fewer people are getting formal support due to reductions in Local Authority budgets, in our case Lancashire County Council.

It is so important to find out how these carers are feeling, and the National Carers' Survey, designed to help the adult care sector understand more about how services are affecting lives, provides some telling answers.

The survey is done every 2 years and covers over 50,000 carers with the aim of finding out whether services are helping carers, which includes the advice and information carers receive and what's available for the people being cared for, for example home help or respite care which enables regular carers can have a break.

Carer's satisfaction is very low, 39% and the reasons for such low satisfaction make dismal reading, having no encouragement or support, being worried about personal safety, self-neglect, not having enough time to care and feeling socially isolated.

The impact of all of this cannot be underestimated, with the detrimental impact of caring on the health of carers well documented, both on their physical health and through social isolation.

Carers are often the 'golden thread' that ensures that care services for individuals are co-ordinated, so it is sad that a significant number of carers have had a poor experience when it comes to being involved/consulted in decisions about care.

In fact only two fifths feel involved and consulted with dissatisfaction declining since 2012.

The types of support carers do value are financial assistance and the ability to work.

Carers in financial difficulty are four times more likely to be dissatisfied than those without financial worries (30% as opposed to 8%).

Those who have been supported to stay in employment and who have the backing of their employers, understanding and flexibility of working hours around their caring responsibilities, are more likely to be content.

As I have said respite is invaluable, access to longer breaks, home help and meals on wheels also help carers.

Carers tell us that having access to information at drop in centres, Ribble Valley Dementia Action Alliance meetings, our café events and activity events really does help them manage better, enhancing their quality of life.

I hope the imminent green paper on social care funding for older people shows the value of care provided by informal carers. The vast amount of work they do combined with how unsupported they feel represents a huge area for change and improvement.

There is also the impact that informal carers make on costs to the NHS which are not included in costing estimates for the future. Future estimates on the financial implications on social care are based on formal care services, the potential cost of contributions towards informal care needs to be factored into this equation.

Above all informal carers need to be supported so that their lives are enriched along with the lives of the individuals for whom they care. It is important that the true cost of care services is out in the open. It is rewarding when carers tell us that they appreciate the time they have to themselves in the knowledge that their loved ones are in safe hands. We want more informal carers to come forward so that they can be supported.

The Older People's Champions Network North West

The Older People's Champions from across the North West met in Lancaster in March for an interesting debate about the NHS and housing health.

We also discussed a subject that is extremely emotive but necessary as we all grow older, and that is end of life. A GP from Lancaster spoke about the increasing need for people to decide themselves how they want to arrange their own end of life as far as possible and to make decisions in advance and be in control of their own fate.

It is the one thing that we all have in common.

The idea is to break the taboo about death and 'death cafes' are starting up for people to get together to drink coffee, eat cake and express their feelings and wishes about end of life. Obviously these are held in a sensitive way with end of life experts but the ones in the Lancaster area have been useful for residents. Simple discussion to demystify and take some of the fear out of end of life awareness can leave people feeling better about it. It is something we are broaching with residents subtly and with care to find out if our own areas are ready for this kind of group discussion.

Since the first Death Café was held in Hackney, North London in 2011, over 5000 have been held in 51 countries.

News from the NHS

The NHS is teaming up with councils to improve health through better housing with home MOTs, falls help lines, stair lifts and heating systems, and quick homes grants.

The cost of poor housing to the NHS is £1.4 billion per year.

Cold houses affect people's health, they can lead to chronic heart and lung disease, heart attacks, strokes and falls as well as poor mental health.

A report by the Kings Fund and National Housing Federation report states that the NHS would save around £848 million if excess cold in homes was reduced to an acceptable level and reducing falls in the home could save £435 million.

2018 marks the 70th anniversary of the NHS and it is time for the NHS and Local Councils to work together to improve health through housing in a more efficient way, making more effective use of funding.

Healthy homes are a significant factor of a healthy childhood and independent later life. Healthy homes are well designed, warm and hazard free, therefore reducing the risk of accidents and major respiratory and cardiovascular hospitalisation.

The NHS Next Steps includes work with councils, housing providers and the voluntary sector to make a difference to people's lives.

It is important that early intervention by councils planning and development departments establishes appropriate space standards and design, particularly for people with dementia and other medical issues.

Three schemes are saving tenants hundreds of nights in hospital, visits to the GP, homelessness and more than £2million in savings is being reinvested into communities:

Integrated Care Systems (ICS) where NHS and Local Government are working together, pooling resources and budgets, is yielding patient and public benefit. Over 40,000 people live in the top 10% most deprived areas in England.

CCGs and housing providers (or Councils where they build houses) are joining forces to provide tenants with the Care Link Responder Service, an alarm with a response team on the end, to help with crises, mainly falls but also no response calls, assistance and reassurance. This saves money for the NHS, as generally speaking, only 7% of falls require an ambulance. Fewer ambulances take the strain off the emergency services.

People just out of hospital get free Telecare while they recover which is a free direct helpline to a falls and mobility team, reducing pressure on the NHS.

A new service with key workers based in hospital wards address tenants' property barriers that may prevent a return home, such as broken heating, cold homes or new mobility equipment needed.

All of these measures enhance care and save money which can be reinvested to improve other health and social care services.

75% of deaths related to falls happen at home and represent 10-25% of ambulance calls to older adults.

Simple home modifications, such as installing handrails, outside lighting and slip resistant surfaces for outside, which cost a few hundred pounds, results in a huge drop in the number of injuries and resulting medical treatment.

Facilities for over 50s

The Lunch Clubs are still doing great business in many of our villages, the Council provides start up finance and many of our residents join in and look forward to the food and social gatherings. It is so important that our residents, especially in the more rural villages, have a chance to meet regularly. This type of facility can prevent social isolation which is a huge problem for society and led to the Government to set up a Commission for Isolation and then appoint a Minister for Isolation in 2017.

Grants can still be accessed for new or existing Lunch Clubs.

Dilys and Amy have a full list of Lunch Clubs if any of your residents are interested, you can reach them on 01200 414549.

Fitness for Life

Fitness for Life is the Council's exercise self-referral scheme for people who may have become inactive, have special medical conditions and would benefit from a specially designed 12 week programme, either in a group or on an individual basis.

Contact the Up and Active Team to book a consultation on 01200 414484

Seniors Forum

Our Seniors Forum is still going strong and they have some interesting speakers. This year they have hosted East Lancs. Hospital Trust's Kerry Herron on a 'Home First' topic, Vikki Armstrong and Nicole Mason East Lancs. CCG on the 'Together a Healthier Future Programme', Craig Pollard from Lancashire Wellbeing Service and Jill Brown from our Council talking about housing for older people in Ribble Valley.

County Councillor Ian Brown awards the Seniors Forum money from the LCC Community Fund which was £350 last year and goes towards the annual Older People's Day in October. We enjoy helping out at that event, it's always well attended and a fun day for the over 50s.There are also events in Libraries across Ribble Valley and at The Platform Gallery to interest our over 50s, just check the website.

Staying Warm and Healthy in Winter

Our Council provides help for older people, in fact anyone who is vulnerable or on a low income to stay warm. There are Government Schemes that can help people to access boiler repairs, service and replacement and the Council can loan out oil filled radiators and help people to switch energy suppliers if they are paying too much with their current tariffs.

The Council can advise people about keeping warm with help from Homewise who will do a home check to identify measures people can take to improve the temperature in their homes. There are also some warm homes packs still available and the Council can give advice on keeping warm and healthy in Winter, including stocking up on food, keeping a stock of grit, free flu vaccine and the Best Foot Forward Programme to improve strength, balance and confidence through exercise.

There is also advice on footwear, tablets and medication, environment and lighting and eyesight and vision.

There are two 'Heat and Eat' to keep warm events coming up, Longridge Civic Hall on 25th October 2018 for everyone and Trinity Church on 31st October 2018 for homeless and vulnerable young people.

There is a 'Little book of Warm' also available from the Council that has recipes and all kinds of tips for keeping warm.

What in the World is a Dementia Village?

Just imagine that you have been diagnosed with dementia, you are in the early stages and have the opportunity to choose how you will be cared for in the future.

What if you could choose between a home setting and a gated community where you are able to share an apartment with friends and have the freedom to go shopping whenever you please.

Which would you opt for?

Well an International senior care community is revolutionising dementia care through dementia villages.

<u>A Dementia Village</u>

The village of Hogeweyk sits in the municipality of Weesp is not far from Amsterdam. It looks like any other village with a cinema, restaurants and shops. Apartments surround a lovely courtyard with trickling fountains and vibrant seasonal flowers which can be admired from the benches situated in prime places around the circular path.

The village is unique, it is home to 152 men and women living with dementia. There are 23 residential units shared by six to eight residents who have around the clock care from 240 'villagers' who are in fact trained dementia nurses dressed in street clothes.

The staff take care of everything, from manning the village shops to cooking meals, planning activities, assisting with bathing, personal care and medication so that the people living with dementia can go about their day. Residents are encouraged to help with cooking and shopping and other household tasks and if they become confused, there is always someone there to help them.

Constant reminiscence therapy paired with the freedom of the village has made a difference to behavioural issues as residents are calmer and less agitated or aggressive which has resulted in a reduced need for high powered drugs and medicine. Some are sceptical about this model but families of residents have said it is the most compassionate type of dementia care available where people can live as normal a life as possible.

Hogeweyk allows residents to eat dinner family style, go to the hairdresser, visit friends or go for a walk in a secure space whenever they wish.

As you can imagine, cost is the greatest barrier to adopting this model of care but how wonderful would it be to replicate it here?

The National Hospital, Queen Square, London

A member of our Ribble Valley Dementia Action Alliance who lost his wife to Benson's disease, a rare form of dementia, recently told me about The National Hospital and the work they do around Dementia.

As nowadays most people turn to The Alzheimer's Society for dementia research, and Dementia Action Alliances for practical help in setting out dementia strategies, dementia awareness sessions, networking and the provision of information and respite care, I thought I would let you know about the work of The National Hospital in the field of Dementia and other serious health conditions.

The National Hospital for Neurology and Neurosciences is a leading centre for the diagnosis, treatment and care of patients with a wide range of neurological conditions such as epilepsy, MS, Alzheimer's, stroke and head injuries. The hospital is part of University College, London Hospital NHS Foundation Trust (UCLH).

There have been some amazing breakthrough in Neuro-rehab, Huntington's and in the early signs of dementia.

Neuro-rehab - Recently The National Hospital featured in documentaries called Richard's War, shining a light on stroke recovery issues.

Richard Gray had a catastrophic stroke and the programmes followed his recovery with Nick Ward, Consultant Neurologist at Queen Square. The hospital's upper limb neuro-rehabilitation programme provides high quality individualised care to stroke patients, where intense physical therapy can make a huge difference, even to people who have been told that further recovery wasn't possible.

Richard was helped by Professor Ward and his team in regaining his mobility and independence by learning to use his hand and arm again in his daily routines through the intense physical therapy programme. Huntington's breakthrough – Huntington's disease is one of the most devastating neurological illnesses. Some describe it as a combination of Parkinson's, Alzheimer's and Motor Neurone Disease all rolled into one, and there is currently no cure.

In December 2017, researchers at The Institute of Neurology made a huge breakthrough. They found that they could successfully lower the levels of a dangerous protein, called huntingin, in the brains of those affected by the disease.

On the trial, 46 patients had a 'gene-silencing' drug injected into the fluid that bathes the brain and spinal cord. This first human trial showed that the drug was safe and well tolerated by patients. Sarah Tabrizi who led the trials said that she had been running a clinic for twenty years and had seen many of her patients die. For the first time she had seen a potential hope of a therapy that one day could slow down or prevent Huntington's disease. This is of ground breaking importance for patients and families.

<u>Dementia – Early signs</u>

A team led by Queen Square researchers has developed a test to spot subtle deficits in memory, years before actual Alzheimer's symptoms develop, giving real hope that the disease could be detected early.

The study involved 21 people who carried the gene mutation for early onset Alzheimer's alongside healthy control subjects.

All underwent a memory test with 30 minute recall, and were then checked seven days later to see if they still remembered.

The researchers found that people who were closest to the expected onset of symptoms could remember things after 30 minutes, but then had forgotten things after seven days. This shows memory formation isn't the issue, so typical tests won't spot problems.

The test could help identify people for early clinical trials, while helping monitor whether a treatment is working.

"It's really a case of accelerated forgetting" says Professor Nick Fox, study lead. "Many people have a feeling that something is going wrong with their memory, but when they take the current test, it doesn't show anything – 30 minutes is not enough time.

The people who carried the mutation did no worse at 30 minutes but at seven days they were quite a lot worse. The difference was really quite remarkable"

Every three minutes someone in the UK develops dementia. There is always an urgent need for people, healthy or affected by dementia to take part in trials. (joindementiaresearch.nihr.ac.uk) Lancashire County Council's Dementia Strategy

Lancashire County Council's Dementia Strategy 2018-2023 was recently launched with a plan to make Lancashire dementia friendly.

The Strategy is aimed at making Lancashire dementia friendly, to help people to reduce their risk of Dementia and to work with partners to help people living with Dementia, carers and families to live as well as possible with what can be a devastating diagnosis.

The County Council acknowledges that as a large employer it has a role in making the organisation dementia friendly as they may have staff with a diagnosis or carers and family who need support as an employee.

The five strategic objectives are:-

1. Take action to reduce the prevalence of dementia in Lancashire

2. Raise awareness of all types of dementia amongst all population groups in Lancashire.

3. Promote early diagnosis and increase diagnosis rates across Lancashire

4. Facilitate action to early treatment and appropriate support to allow people with dementia to live well and independently.

5. Become a 'Dementia Friendly ' organisation.

It is essential that people have an early diagnosis as people can live well if they have the information, support and skilled care they need.

Whist there is currently no cure for Dementia, simple things such as enabling people to take part in everyday activities can help people live well, and medication to slow progression of disease can reduce and delay the need for health and social care services.

Life expectancy in Lancashire is increasing but healthy life expectancy is falling so it is so important to understand that the risk of dementia is significantly increased by type 2 diabetes, high blood pressure, high cholesterol, obesity, brain damage as a result of drug and alcohol use and air pollution. There is evidence to show that the risk of Alzheimer's disease and Vascular Dementia can be reduced by following a healthy diet, regular physical activity, ceasing smoking, and regulating alcohol consumption, avoiding illicit drug use, remaining mentally active and breathing clean air.

Lancashire works with key partners, Dementia Action Alliances, NHS England, Age UK, CCGs, Alzheimer's Society, volunteers including people living with dementia, carers and families.

LCC have introduced 'Playlist for Life' recognising the power of music in dementia to unlock memories, stimulate and connect with others.

Playlist for Life is being piloted in care homes in East Lancashire with a view to full roll out in the future and linking with 'Singing for the Brain'

ATTILLA, an assistive technology and telecare system designed to maintain independent living at home is a registered clinical trial which LCC are involved in, the results of which will be published in September.

LCC have embraced the issues of housing environments and planning with respect to dementia. This involves working with partners assess current and potential housing against dementia standards so that housing associations can collaborate and develop action plans to make their housing dementia friendly. Ensuring that planning services are in tune with the ageing demographic ensures that housing types are in tune with housing need.

LCC have agreed that partnerships with Dementia Alliances and Dementia Friendly Communities is beneficial, good examples of bringing people together to support people living with Dementia.

National Policy

<u>Current national guidance and best practice specific to dementia</u> clearly defines core themes which are:-

- <u>Health Information and awareness raising</u> Dementia health campaigns need to be locally relevant, especially for those with undiagnosed dementia and everyone living with dementia should be given details of local services from both voluntary and independent sectors.
- <u>Dementia prevention</u>

Actions to prevent dementia should be strongly promoted as they are cost effective and have an impact on later disability.

• Early diagnosis

The core message in all the guidance is the importance of early diagnosis, and NHS England set a target that two thirds of people with dementia are diagnosed. Clear pathways should be developed for Health and social care professionals to enable them to deliver diagnosis, referral and care.

• Early Treatment and support

The benefits of early diagnosis are best realised by prompt advice and support to signpost newly diagnosed people to local services. Carers and families need support as well and Dementia Hubs are invaluable for providing an array of information.

- <u>Social actions and integrated care</u> The challenge of dementia needs a collaborative response to build Dementia Friendly Communities. By 2020 all tiers of Government should be part of a Dementia Action Alliance.
- <u>Maximising Independence</u>

All services should aim to maximise the independence and quality of life of people with dementia. Homes and environments must be made dementia friendly to prolong independent living and reduce the number of care home residents.

• High quality Social Care

Care homes should have a named lead staff member for dementia. Many people with dementia living in care homes do not have their health needs regularly assessed and reviewed and this ultimately results in hospital admissions. Residential settings should cater for the needs of different groups and their carers with regard to age, health issues and culture.

• <u>Support for Carers</u>

Providing carer support is most important in dementia care and carers must have an assessment of a person's needs and a support plan which should be individualised and have interventions.

• Preventing abuse

People with dementia are known to be an at risk group in terms of abuse, particularly financial exploitation, theft and fraud. Local services are responsible for protecting and safeguarding people with dementia and staff should have training on abuse and neglect.

There is a huge amount of work to be done by LCC, health care providers, enablers and those delivering dementia services. However we can help to make life better, and whatever time we can give really does make a difference to people living with dementia and carers, particularly in providing information, activities and respite care.

Councillor Sue Bibby

Ribble Valley Older People's Champion

Chair Ribble Valley Dementia Action Alliance