

Dementia Action Week



Hello and welcome to this special Dementia Action Week edition of the Knowsley Carers Centre newsletter. Over the last 12 months the coronavirus pandemic has made caring for a person affected by dementia more challenging than ever, but in Knowsley you are not alone. Lots of work has been done to bring services and organisations together to support you.

Dementia Action Week is an opportunity to celebrate the contributions of carers and the vital role you play in keeping a loved one safe and well. It is estimated that unpaid carers across the UK save the government around £11 Billion per year (Alzheimer's Society, 2014) and over what has been an even more challenging year, Carers UK estimates that carers have saved £530 million

To access services from Knowsley Carers Centre please Tel 0151 549 1412 leaving clear contact details or email to enquiries@knowsleycarers.co.uk

per day. But what really matters is celebrating and recognising you and the real difference you make to the life of someone in supporting them to live well with dementia.

The week is also a chance to raise awareness. Knowsley is working towards becoming a Dementia Friendly Community, involving a vast range of people, services and businesses who can contribute to making Knowsley a good place to live well with dementia. Knowsley Dementia Partnership Board plays a vital role in this, bringing people together, driving change and encouraging better awareness. We're all excited to see what this brings in the coming year!

The national theme of Dementia Action Week 2021 is about social care reform. People living with dementia are the largest users of social care services, accounting for 60% of home-care services and 70% of people in care homes. Transforming the social care system will have a huge impact on the quality of life of so many people affected by dementia today and for future generations to come. So, you might also see some campaigns about this between 17th – 23rd May.

As usual, you'll find lots of interesting and useful items in this month's newsletter and some brilliant support for carers in Knowsley. Enjoy!

Hayley Winstanley, Alzheimer's Society Knowsley

**Dementia
Support
Knowsley**



Living with dementia at any time brings challenges. If you need support we are here for you in 2021.
knowsley@alzheimers.org.uk

How to get personalised one-to-one support

Contact our Knowsley dementia support worker between 9:00am - 5:00pm Monday to Friday

Melanie Campbell
melanie.campbell@alzheimers.org.uk
07525 403 832 or 0151 426 4433

We can help with issues such as:

- Understanding a diagnosis of dementia
- Legal matters including Lasting Power of Attorney
- Managing your money and benefit entitlements
- Living well with dementia and keeping active
- Support with everyday tasks and getting further help



Knowsley Carer Information and Support Programme

Join us for five weekly sessions
starting 15th June 2021

The course runs for 5 consecutive sessions
covering topics such as:

- Understanding dementia
- Legal and Money Matters
- Coping with change as dementia progresses
- Where to get further support
- Living well and activities

Here for everyone
affected by dementia
alzheimers.org.uk

Get in touch today

knowsley@alzheimers.org.uk

0151 426 4433





Dementia Action Week is a national event that encourages people to take action to improve the lives of people affected by dementia.

One in three of us born in the UK today will go on to develop dementia in our lifetime, and there will be one million people living with dementia by 2025 making dementia care one of the greatest challenges facing our society. We all have a role to play in making the UK a dementia-friendly place to live and that's what Dementia Action Week is all about.

Knowsley is marking Dementia Action Week in a number of ways, and we invite community members and partners to get involved:

- Attend one of our Dementia Action Week activities (see details below)
- Help us develop the next Knowsley Dementia Strategy
- Cure the Care System (sign the petition)
- Sign up to attend a Dementia Awareness Session
- Send us a Patient Story highlighting people living well with dementia

Developing Knowsley's Dementia Strategy

We are inviting those who live with dementia and their families to help shape the next Dementia Strategy by providing their views in a questionnaire available soon on the Carers Centre website. A separate questionnaire will be available to agency professionals who support people living with dementia.

Sign the petition

Right now, the broken social care system means that in the UK, nearly 1 million people with dementia, by far the majority of social care users, and their families are struggling to get the support and dignity of care that they deserve. [You can sign the Alzheimers Society petition here.](#)

Dementia Awareness Sessions

During these friendly and interactive *sessions* you'll learn more about *dementia*, how it affects a person and what you can do to help people affected by *dementia* in your community. Big or small, every action counts! *Sessions* lasts around 45 minutes and will be delivered via an online webinar or a livestream video. Register your interest and we'll provide details of dates and times when sessions will be delivered.

Date Time	Activity	Lead organisation	How to join
Tues 18 th May 9:30 – 11:30	Dementia Awareness Webinar (Via Zoom)	Sight and Mind/ One Knowsley	Book your place by contacting Jacqueline King Jacqueline.King@OneKnowsley.org (please book by Thur 13 th May latest)
Weds 19 th May 10:00 – 11:00	Information Session: Getting Your Point Across: Ask, Negotiate, Advocate <i>This session offers strategies, tips & hints to help you prepare for tricky conversations & get your point across effectively.</i>	Together In Dementia Everyday (TIDE)	Please register in advance: (click here) You can also dial-in to this session by phone – contact 07704 168867 for details
Thurs 20 th May 11:00 – 12:00	Expert Panel <i>Join this Zoom session to find out more and ask questions about Dementia support in Knowsley. The panel will include members from NHS Commissioners, Alzheimer’s Society, Support Services, Clinicians, and those affected by dementia.</i>	Knowsley Dementia Partnership Board	Please register in advance. You can also dial-in to this session by phone. Contact Mark Gill: Mark.Gill@healthwatchknowsley.co.uk 07566 789411
Fri 21 st May	Young Onset Dementia (LCR activity) <i>Four short one hour workshops throughout the day on Friday 21st May, starting at 10.30am with the last one at 6pm in the evening. They will include a couple of presentations and a short time for questions.</i>	Alzheimer’s Society	For more information contact Knowsley Alzheimer’s Society on 0151 426 4433 or email knowsley@alzheimers.org.uk

Come along to our singing group

Join other people with dementia at a Singing for the Brain® session in our online virtual Zoom sessions

Our Singing for the Brain sessions use singing to bring people with dementia together in a friendly and stimulating activity.

Where to find us?

<https://zoom.us/join>

Meeting ID: 640 8922 4273

Passcode: 1234

Contact us for help using Zoom!

Our Singing for the Brain® session runs

Dementia Action Week!: Monday 17th May
2pm-3.30pm

'I love Singing for the Brain® which I call singing for the soul. The group lets me meet other people with dementia, which makes me feel that I am not so different after all.'

Irene, who has dementia



To find out more
contact us on:

knowsley@
alzheimers.org.uk

07525 403 832

alzheimers.org.uk





one
KNOWSLEY

As part of Dementia Awareness Week 2021, Sight and Mind (CIC), in collaboration with One Knowsley's Social Prescribing Team, will be running an Introduction to Dementia Awareness webinar **FREE** to all of Knowsley based organisations within the Community, Voluntary, Faith and Not for Profit sector – volunteers, staff and service users.

The numbers of people living with dementia globally is increasing rapidly. In Knowsley there are currently around 1700 people living with dementia. However, it is estimated by 2030 the number of people aged 65 and over living with dementia in Knowsley will increase by 33%. This webinar will raise awareness and share insights into what dementia is and how people living with dementia can live well.

The Webinar will be taking place via Zoom on Tuesday 18th May 9.30- 11.30 am.

If you are interested in attending please book your place by emailing Jacqueline.King@OneKnowsley.org by Thursday 13th May.

The Webinar will cover:

- What is dementia?
- The impact on the person and their family, friends and colleagues.
- The importance of living well with dementia and the possible barriers and hurdles.
- Person centred practice and why it is vital.
- Transition stages.
- Words and behaviours to avoid. Identifying stresses and triggers.
- Disorientation with time and place.

Have you requested a Carers ID Card?

Over the past year 1333 new Carers ID cards have been issued. The demand for cards has increased as carers are finding that due to the current restrictions, they need to prove they are a carer. So far 26% of all our carers have a card.

Many carers have told us that they have used them when the person they care for has a medical appointment so that they are able to stay with them.

Carers who live separately to their cared for have been able to prove that they are travelling on legitimate business. Some of our new referrals have come to us on the recommendation of the police, the Hospital Discharge Team and the carer links in GP practices.

We recommend to all carers that they tell their GP that they are a carer. If your cared for is registered at a different GP the card can be used to prove that you are a carer there too. It is worth doing this as surgeries will then be more accommodating over the times of appointments and reordering of your own medication to fit around your caring role.

If you would like to have a card, please send me a head and shoulders photo by email to judy@knowsleycarers.co.uk If you would like more information you can email me or call me on the number below.

If you don't have email you can send me a photo by text to 07525 638 093. Don't forget to tell me who you are!

Helped us get seats with more legroom on the plane.



I've used mine when we have been together to the cinema so I have got in for free.

Do you have a Carers ID Card?

I forgot the Disability Concessions Card but my Carers Card was taken as proof instead.

Sometimes when booking events I show the card as proof that I need the same access as him.



We need your help

Sight and Mind provide tailored support, guidance and advocacy to individuals and families caring for a person living with Dementia and/or Sensory Impairment in Knowsley.

As part of our independent research into the provision of services within Knowsley, we would like to hear from carers in the borough who are supporting a person living with Dementia and/or Sensory Impairment.

- What is the true reality of becoming a carer for a person living with Dementia and/or Sensory Impairment?
- What are your concerns?
- What could be improved?

We would value your views and experience.
Everything will be treated in confidence.

Call 07516 529093 Monday-Friday or email ceciliatoole@sightandmind.co.uk

sightandmind.co.uk

TO CONTACT KNOWSLEY CARERS CENTRE

Knowsley Carers Centre continues to provide services during the Covid 19 outbreak. You can contact us in the following ways.

Leave a clear message and contact details on Tel: 0151 549 1412

By email to enquiries@knowsleycarers.co.uk



A 'CUPPA' For Carers

Mobilise is an organisation providing a daily e-support package for carers through the Covid19 pandemic. Carers can sign up for the daily mailing here:

<https://james816492.typeform.com/to/NZSI88>

They are running a virtual 'Cuppa' for carers at 4pm, which is proving popular: www.mobiliseonline.co.uk/cuppa

Technology to help with dementia

Knowsley Council can offer a variety of devices to help support people living with or caring for loved one's with dementia.

Door-Exit Sensor

If the person with dementia exits their home unsafely the door sensor will send an alert either to someone else in the property or the Alarm Receiving Centre.



Bed occupancy sensor

If the user gets out of bed and does not return within a specified period of time the sensor will alert a carer or the Alarm Receiving Centre.



Memo Minder

This sensor is located near the front-door and can have a recorded message in the voice of a carer reminding the cared-for not to leave the house or to remember take house-keys, for example.



GPS device

If someone with dementia leaves their home but begins to wander un-safely the Pebble GPS device can send an alert to a carer to let them know their whereabouts and then take appropriate action.

Robotic pets

People with dementia can find caring for an animal to be a source of support and stress-relief as well as providing a sense of purpose. These robotic pets are battery operated and can move and make noises. The Council have a range of other assistive technology devices to help people live safely and independently. The equipment is free but monitoring charges will apply if any device is linked to the Council's 24/7 Alarm Receiving Centre. There is no monitoring charge if a sensor is being monitored by a carer who lives in the same property.

For more information call Home Care Link on 01695 585 224 or email

telecare@westlancs.gov.uk





Tide (Together in Dementia Everyday): The Experiences of Carers of People Living with Dementia during the Covid- 19 Pandemic

Tide is a charity that focuses on supporting carers of people living with dementia to recognise their own value and use their lived experience to influence positive change in policy, research and services. Our research during the pandemic found that carers felt their own needs, as well as those of the person they care for, have been ignored by government and decision-makers.

Practical Issues

People living with dementia have been particularly vulnerable during the Covid-19 pandemic, causing additional stress to carers and an increase in hours spent caring due to reduced support, withdrawal of services, lack of respite, self-isolation and shielding. Many carers expressed concern about deterioration in the symptoms of the person they care for due to lack of social interaction and cognitive stimulation, leading to increased complexity of care.

‘I’ve been unable to attend to my Mother’s personal care needs as care calls ceased several weeks ago, unable to assist my Father to care for her. I was

unable to offer the emotional support my Father needs or respite for him. My Mother has lost all motivation or direction as the day centre was the focal point of her week prior to this. She has rapidly declined.’

Services for People Living with Dementia

Lack of services and support for the person they are caring for has been the main source of concern to carers. It is still unclear when some services will re-open and what they will look like when they do. Carers expressed worry about whether the person they care for will still be eligible for support, not hearing from adult services, and cases being closed or put on hold.

‘I had a phone call from the social worker saying Mum’s case was being closed. I had such a struggle to get an appointed social worker. I couldn’t believe, especially in these circumstances, that support has been withdrawn.’

‘When the need for support arose, it very quickly became apparent that there was NO emergency care or support available and we were left to fend for ourselves.’

Visiting Care Homes and Hospitals

Many carers told us about their distress due to not being able to visit their loved ones in residential and care homes.

‘I can’t visit my mum in the care home. I can see her through the lounge window but not being able to physically be in the same room and hold her hand is hard to deal with emotionally for me. Especially as there is no time limit on how long this situation will last.’

‘Not being able to visit my Mum in her care home - the way she was going, she

might not know who I am when I eventually get to see her.'

The Impact of Caring for People Living with Dementia during the Pandemic

Carers have found themselves ever more isolated and at much greater risk of negative impacts on their health and wellbeing. Many are still restricted to their homes and likely to stay there even while other people are emerging from lockdown. Some carer support services have been able to put virtual support services in place, but not all of them and, whilst it is true that some carers have been able to access more flexible online activities than would usually be the case, many carers are unable to access virtual support at all. Many carers have described feelings of grief and loss and,

24/7 with limited support as causing stress, lack of sleep, lack of respite, isolation and loneliness, anxiety and worry, and the struggle of having to manage mental health for both themselves and their loved one.

'I was struggling before the lockdown, but at least I could get away for a couple of hours from caring. That lifeline has been taken away'

'Self-isolation and social distancing is nothing new to the caring role. I have been feeling totally isolated for over 10 years now and, if I thought that it was bad before, since the lockdown it has escalated beyond belief.'

'No-one Is Talking about Unpaid Carers'

During Carers Week in June 2020, many carers expressed anger. They described a loss of identity for carers during the pandemic as the media started referring to all health and social care workers as 'carers' and that, ironically, during a week with the theme of 'Make Caring Visible', they had never felt less visible.

'I care for my husband at home and I have many friends,

colleagues, fellow travellers, who care for someone in another setting. We all face challenges daily, during this era of Covid-19; very little of which is being aired in public. Talk of 'heroes' is the dominant narrative. Probably because it is easier, 'better', to keep things positive. No-one is talking about unpaid carers because no-one knows what to say.'



where there has been bereavement, an impact on the ability to provide end of life care.

'I am finding it depressing as I am having to deal with my bereavement and isolation, and I fear for my mental health at times'

Carers talked about the effects of caring



Mersey Care
NHS Foundation Trust

Transfer of North West Boroughs Healthcare Trust's Cheshire and Merseyside staff and services to Mersey Care NHS Foundation Trust

Having explored various options, in November 2019, the NWBH Trust Board and Council of Governors recommended to the regulator NHS Improvement that being acquired by Mersey Care NHS Foundation Trust would be the best way to support the continuation of high quality and safe care to local communities in the long term future. This means subject to approvals processes, the community and mental health services delivered across parts of Cheshire and Merseyside and the staff who deliver them will transfer to Mersey Care NHS Foundation Trust on 1 June 2021.

This will be positive for patients, service users, carers and staff across both trusts. There will be no immediate changes to patient care, just a change to the logos you may see at clinics and on your appointment letters. If you have any questions or would like further information please email:

Merseycareinfo@merseycare.nhs.uk

Tide Activities

Tide has always been about the voice of carers and it is clear that this needs to be listened to urgently by government and decision-makers and that access to physical and mental health services, social services, respite and crisis support for carers must become a priority. But, along with many other organisations, we have responded to the pandemic by moving much of our activity online and developing new activities according to what carers say they need. As well as involvement and co-production opportunities, carers can now choose from:

Virtual Coffee Mornings: Local and UK-wide

Workshop Sessions: You Can't Pour from an Empty Cup; Living Grief and Bereavement; Getting Your Point Across - Ask, Negotiate, Advocate; The Practical Carer

Facilitated Peer Support Groups: Carers of people living with Young Onset Dementia, Home Carers, Former Carers, Carers of people in Residential Care, Male Carers

You can become a member of Tide by signing up here:

https://www.tide.uk.net/join_tide/

If you are interested in getting involved, have any questions, or would like to chat, please contact Sarah Butler-Boycott - Carer Involvement Lead (Merseyside and Cheshire)

Email: SarahBB@tide.uk.net

Phone: 07704 168867



Discover the benefits of spending times in the great outdoors

As the days get lighter and longer and spring brings more colour and wildlife into our gardens, parks and green spaces it's a wonderful time to escape outdoors and experience the benefits of nature on our health and wellbeing. We know that people who spend time in nature are happier and healthier – which explains why nature is the theme for this year's Mental Health Awareness Week, from 10 to 16 May. Spending time in the great outdoors is known to be an effective way of supporting our mental health and wellbeing which is especially important in helping to deal with the stresses and demands of caring for a loved one. It's also a great way to keep active too, going out for a short walk every day, breathing in fresh air and taking in the sights and sounds around us can help to lift our mood and help us to destress after a busy day.

Connecting with nature

It's important to switch on your senses and really connect with nature; you

could stop to listen to the birdsong, smell the freshly cut grass or notice any trees, flowers or wildlife or animals nearby. It's about making time to notice and appreciate the natural world around us, Knowsley Council's Green Spaces team has come up with some great ideas to help us stay connected with nature. The fab guide has a section on stargazing with hints and tips about the best way to view night time skies, as well as a bird watching fact sheet, which is an activity you could perhaps do with the person you care for from the comfort of home. Also, tips to improve your wellbeing and how to find out more about nature on a trip to your local Knowsley park, the guide has something for everyone!

[There's more about the guide and how to download it here.](#)

For more information about parks and green spaces in Knowsley visit the council's website, www.knowsley.gov.uk or email:

...the great outdoors

dns.sustainability@knowsley.gov.uk

Taking part in the Knowsley Sunflower Challenge is another great outdoor activity which anyone can join in with and enjoy. No gardening experience is necessary thanks to the Knowsley Flower Show step-by-step guide to growing a sunflower. And, if you can't get hold of sunflower seeds, a supply of seeds, kindly donated by Halewood farmer Olly Harrison – is available for you to use by contacting the council.

[Find out more about the Knowsley Sunflower Challenge](#)

The [Healthy Knowsley website](#) has lots of top tips and activities which can help you to make positive lifestyle changes to boost your mood, get active and help you feel good about yourself.

Meanwhile, if you are feeling anxious, worried or low [Kind to Your Mind](#) has lots of advice and useful resources to help look after your mental health. It is home to [ALMA](#) – the dedicated health and wellbeing website with a range of free online therapy programmes to help you deal with stress and getting better sleep to improving resilience and coping with your emotions.

You can also get a free NHS-approved Mind Plan from [The Better Health - Every Mind Matters website](#). Simply answer five quick questions you will get a free plan with practical tips to help you manage stress, sleep better and boost your mood.



Young Carers Service

During the current lockdown measures our Young Carers Service is accepting referrals and we can now conduct home visits to complete Young Carers Assessments. Alternatively, this can be done over the telephone if you are not comfortable with us visiting.

We can provide advice or support over the phone and we're available to chat.

The Me Time programme provided by Vibe is up and running, they are providing our Young Carers with activities that they can do together in safe environments like in the park. Please feel free to contact us on 07717 301 325 – Chris Wong if you would like further information or know any child/young person who is looking after someone and would like support.



THE CARER'S EMERGENCY CARD



Peace of mind for carers in Knowsley

What is the carer's emergency card?

If you look after your partner, disabled child, relative or friend who relies on your support you could receive a carer's emergency card. If you were involved in an incident, accident or emergency, then you, another person or the emergency services would use this card to contact the 24 hour telephone response service to make sure the person you care for is safe and well. By carrying one, ideally in your purse or wallet, you can be confident that the person you care for won't be left without the support they need.

How much does it cost?

Nothing – the card and any emergency care that may be needed in the first 48 hours is free to all carers resident in Knowsley.

How to register with the Carer's Emergency Card scheme

You can download a registration form from :

http://www.knowsleycarers.co.uk/forms/6084.18_carers_registration_form.pdf

Once completed it should be posted to :
Home Care Link (CC)
Freeport LV5348
Ormskirk, Lancashire, L39 2HT

healthwatch
Knowsley

Your views and comments
are important to us

Healthwatch Knowsley makes sure your views on local health and social care services are heard. If you have received a service from Knowsley Carers Centre—whether that be information support, advice or any other service, please feedback your comments to the Knowsley Healthwatch website www.healthwatchknowsley.co.uk

If you are using the Healthwatch Knowsley website to leave feedback about Knowsley Carers Centre, why don't you leave feedback about your GP surgery at the same time? It is really important for us to hear how people are accessing services.

WELFARE BENEFITS ADVICE



Our Benefits Advisor, Paul Murphy continues to provide telephone advice, information, benefits calculations, and support to help complete forms.

Please call on 0151 549 1412 leaving clear contact details or email enquiries@knowsleycarers.co.uk

‘What? Your dad has dementia and lives at home on his own? Shouldn’t he be in a care home?’

I cannot count the number of times I’ve heard this question! Dad was diagnosed with Alzheimer's in March 2013 and, since then, we have put good systems in place to enable him to do as many things for himself as he can. As the Alzheimer’s progresses, we are gradually adding in more support. But with a lot of support from myself, my amazing partner, private carers and family members, my Dad is successfully continuing to live independently and happily in his own home.

The first few times I was asked this question, I really questioned my Dad’s care. Was he safe living on his own? Was I putting him at risk? Was he in danger? Back then, in the early years of Dad’s diagnosis, we didn’t have much support. By the time we did get support, we had already figured a lot of things out on our own. But the same question kept coming up, and it was like a knife to my stomach. I started to feel guilty and it made me doubt myself and question the care and support I was providing for Dad.

In 2017, at the Alzheimer's Roadshow, I talked to someone who had set up a care company specialising in caring for people living with dementia. We didn’t yet need the washing, dressing and preparing meals that care services tend to provide, but this service offered companionship, which was the main thing Dad craved because friends and family couldn’t be



Hayley with her Dad

around during the day and I was working full time. We arranged 3 visits a week and, although my Dad had always been against the idea of ‘carers’, these carers were introduced as companions. These amazing companions were able to give me peace of mind that Dad was OK whilst I was at work. It didn’t take long for my Dad to come round to the idea of ‘carers’ and look forward to his visits. Things were easier with this support in place, but still that question was thrown at me - **‘Should he not be in a care home?’**

By now, the question was starting to feel judgemental. I would find myself having to explain to friends, family, colleagues, and strangers why a care home was not suitable for my Dad at this stage. They would usually look at me and nod, but their faces said ‘I’m not convinced’ and I would leave with that sinking feeling in my stomach - doubt and guilt that I wasn’t doing a good enough job.

In December 2018, Dad was admitted to hospital with pneumonia and developed delirium while in there. He was out of his routine, in a strange environment and sedated due to his upset at not being allowed to go home. He was assessed by

a team who had never met him before the admission and did not spend time with me getting to know his situation. They tested him on making a cup of tea (in an unfamiliar kitchen) and asked him to walk up the stairs (which he failed because he went up a step at a time, like most people, rather than putting his right foot on the step and bringing his left foot to join it!). Based on a couple of weeks observation and a failed cup of tea and stair test, their opinion was that Dad should be in a care home and was not safe to go home. I was horrified. Before going into hospital, Dad had been doing fine at home.

Fortunately, I had Power of Attorney for Health and Welfare and was able to override their decision. I requested that Dad be given the chance to go back home before considering a care home.

Naturally, I was worried because Dad had been out of his own environment, but I wasn't prepared to give up on him that easily. Some of the hospital staff made unhelpful comments - **'What, he's going home?'** **'He lives on his own?'** **'What if he goes outside?'** - I bit my tongue.

The day we took Dad out of the hospital I was worried sick, but I needn't have been. My instincts and experience from years of caring for Dad were right. Within 2 weeks, once the hospital medication had worn off and the reablement team had reduced their number of visits, Dad was doing well and 90% back to where he was before going into hospital. But still that gut-wrenching question was haunting me - **'Would your Dad not be better in a care home?'**

It is now almost 2 years since Dad came out of hospital. He is still doing really well at home, although his dementia progressed throughout the Covid

pandemic and he now needs more help with personal care and preparing meals. But although it may not live up to what society rates as perfect, he has a good quality of life. He may wake up at 3am, thinking it's morning, get showered and dressed. He may have his breakfast, watch TV, and then fall asleep in his chair, but who cares? He is not hurting anyone. He has his independence, and he is happy. He doesn't have to have the same routine as the rest of the world. He doesn't have to be up for work or in bed at a certain time. He can get up when he wants and sleep when he wants, and it works for him.

What have I managed to learn throughout this difficult experience?

- Although professionals may be experienced in dementia, many do not have first-hand experience of day-to-day caring
- Whilst I am not a professional and not an expert in dementia, I am an expert when it comes to my Dad and his dementia journey
- I am doing a good job of keeping my Dad safe and happy at home.
- I have been able to give my Dad an amazing gift in helping him remain at home for as long as possible.
- I now have confidence that everything I am doing is in my Dad's best interest. Whilst dementia is taking a lot of things away from my Dad, together we are making sure it is not taking away his independence, dignity and happiness



**Hayley
Thompson**

Direct Payments

Giving you CHOICE and CONTROL

Do you have health and social care needs - or know someone who does?

did you know?

- you can choose how your care and support is provided
- you can decide who does your care and when it happens

To find out more about Direct Payments and how they can help.

Call us on **0151 480 8873**

Email: info@kdc.org.uk

Visit our website: www.kdc.org.uk

We make it simple and straightforward for you to use Direct Payments and with our help you can employ your own carers (personal assistants).

OUR STORY – PAUL AND MURIEL

My wife, Muriel or Mu as we all know her, grew up in Aigburth Liverpool. I was lucky enough to meet her at a church youth group back in 1968. My dad introduced us by initially asking me if I would teach someone to play the guitar, and although I was reluctant at first, when he mentioned I would be teaching a girl I soon accepted the challenge. Me being only 15 at the time, this made me very popular with the other lads! As it turned out, Mu wasn't great at the guitar, but she did have a fantastic singing voice, and sounded just like Karen Carpenter. We went on to form our own country-rock duo called 'Running Free', writing our own songs and backing tracks.

Mu eventually started working for the bank. She had great typing speed and was good at shorthand. I meanwhile went to college, and then onto a gent's outfitters, and later working in the post-mortem rooms on call for the coroner. My final and most rewarding job was working for Victim Support in the court.

We married at exactly 12.30pm on 26th August 1972. We moved into a flat in Netherleigh and later onto Knowsley and have three daughters who have been a fantastic support throughout this journey. Having had my own struggles with Bipolar Mu looked after me most of the time, but a few years ago we both noticed her memory was getting worse. We went to the GP where she had a simple test, and then onto the memory clinic. At that time, they didn't find anything significant to warrant a diagnosis. But a few months later when things still seemed to be getting worse, we went back. This time they did give us a diagnosis – Alzheimer's Disease. We didn't know what to think at

first. We didn't realise what it even meant. Over time we learned more about what a terrible disease it could be, Mu's memory continually getting worse and me feeling depressed coming to terms with it. I was now her carer.

Eventually I realised I had to pull myself together, and that this wasn't just about me, it was about Mu. I looked for information and support, getting involved with a Carers Course from Alzheimer's Society and support from the Carers Centre and lots of other services. I learned not to bombard Mu with instructions and to get rid of distractions, make eye contact and keep things simple. I struggled to manage finances, but my daughter stepped in to help. I opened up and spoke to people about how I was feeling, asking for support when I needed it. I still have days when I struggle and feel down, but somehow, I pick myself up.

There are lots of positives: Mu still goes for walks with the dog independently and trips to the local shop for one or two items. Recently we've enjoyed listening to the Beatles together and Mu remembers all the words! I find things for us to enjoy together, and we are both looking forward to getting a car again soon so I can take her on a trip down memory lane to some of the places she used to go, as well as some days out and even shopping together again. We also now have eight grandchildren to keep us entertained! Whilst it isn't the way it used to be, we still manage to have a laugh and poke a little fun at each other. It is a hard road but we are still smiling!

My carers top tip: Good communication!



Links you may find useful

Dementia Carers Count: Virtual Carers Centre

A new Virtual Carers Centre has been set up, including tips on managing stress, challenges and solutions & bite-size learning [Visit Website](#)



Dementia UK: Helpline and Information

Dementia UK Admiral Nurses offer practical and emotional support to families on 0800 888 6678 or email: helpline@dementiauk.org. [Visit Website](#)



House of Memories: App and Activities

Created by and for people living with dementia, explore the Museum of Liverpool and archive objects or make a digital family album: [Visit Website](#)



The Brain Charity: Information and Advice for all Neurological Conditions

Information, advice, physiotherapy through dance, speech and singing workshops, information and advice, carer advocacy, counselling: [Visit Website](#)



Tide (Together in Dementia Everyday): Living Grief and Bereavement Resource

Find out more about this project exploring the complex feelings of grief carers can experience when they care for a person with dementia [Visit Resource](#)



University of Worcester: TANDEM Creative Activities

2 Booklets containing creative and sensory activities for people and families affected by dementia, from TANDEM, University of Worcester [Booklet 1](#) / [Booklet 2](#)





More useful Links



Alzheimer's Society – Making your home dementia friendly

<https://www.alzheimers.org.uk/get-support/publications-factsheets/making-your-home-dementia-friendly>



Alzheimer's Society – Memory Handbook

<https://www.alzheimers.org.uk/get-support/publications-and-factsheets/memory-handbook>

Dementia UK – Tips for Better Communication

<https://www.dementiauk.org/get-support/understanding-changes-in-behaviour/tips-for-better-communication/>



British Heart Foundation – Understanding Vascular Dementia

<https://www.bhf.org.uk/informationsupport/publications/heart-conditions/vascular-dementia-quick-guide>



Explaining dementia to children and young people

https://www.cogsclub.org.uk/carers/files/milk_oven.pdf



OUR WALKING GANG



Hi my name is Tammie and I'm in the process of becoming a volunteer with Knowsley Carers Centre, I am also the founder of a walking group that goes by the name of Our Walking Gang. I set

this group up last year when lockdown rules began to allow people who suffer from depression and anxiety to get out and about with the aim to "WALK AND TALK" and the group became a bigger platform to other's who love to get out into the community and push themselves out of their comfort zone. We love to explore the great outdoors from mountains, scenic canal walks, beautiful parks, etc. Since I started the group, we have tackled numerous different walks including Ingleton falls, Snowdon, Red Screes, Rydal Caves

The people we have in our group are so positive, really fun people to be around. Anyone is welcome on our walks and don't worry if you don't know anyone, no one in this group really knew each other until they came to walk with us and now the friendships that have been made will last a lifetime. We have a retired professional mountain guide within our group who helps and supports us every step of the way. When we are on a walk, we never push anyone to go at a pace they are not comfortable with, we have one rule only **WE DON'T LEAVE ANYONE BEHIND.**

I would love to organise some person-centred walks for carers that will allow you amazing people to get out and about for the day, get your walking boots on, meet new friends, have some fun and



maybe even smash a few personal goals. All you will need to go do is turn up; I'll make sure the walk is suitable for all members who would like to go. Whether it's a walk in a local park or you're pushing your limits to a mountain we will have fun and I promise, you will go home with a smile on your face and a feeling of fulfilment. If you think this is for you then get in touch.

For more information contact Ian at Knowsley Carers Centre on Tel 0151 549 1412 or visit the Our Walking Gang Facebook page [here](#).



Updated Knowsley Parent Carers Voice

VIRTUAL SEND COFFEE EVENTS

Tuesday - 11/05/21 - 10:30AM - 12:00PM

Wednesday - 09/06/21 - 12:00PM - 1:30PM

Tuesday - 14/09/21 - 10:30AM - 12:00PM

Friday - 15/10/21 10:30AM - 12:00PM

Friday - 03/12/21 - 10:30AM - 12:00PM

**To book onto any of the above events please email
KPCV on infokpcv@gmail.com**

Please note, Zoom link sent morning of event.

OTHER SUPPORT

AVAILABLE
DURING THESE
CHALLENGING
TIMES



We know that the pandemic is presenting many challenges for our residents and that food is just one thing that you need support with.

Whether it's advice on employment and training opportunities, how to manage your budget or just someone to talk to, help and support is available.



Help and support if you're self-isolating

Help and financial support is available if you're self-isolating. Find out more on the Council's website – www.knowsley.gov.uk (search Test and Trace support payment).

In addition, the Knowsley Support and Volunteer Line – **0800 073 0043** – could help you with picking up shopping, medication, dog walking or just someone to talk to.



Citizens Advice Bureau

For a range of impartial, independent and confidential advice, including benefits and debt advice, email advice@citizensadviceknowsley.org.uk, visit www.citizensadviceknowsley.org.uk for further information or a webchat or call **0808 278 7839**.



Financial advice and support

The Money Advice Service – www.moneyadviceservice.org.uk - has some useful advice about budgeting, avoiding debt and being open about money troubles. Visit their website or call **0300 500 5000** for free impartial advice.

Stepchange provides advice around debt management. Further information is available at www.stepchange.org or by calling **0800 138 1111**.

For money saving tips and budgeting advice, visit Martin Lewis' Money Saving Expert's website at www.moneysavingexpert.com. You can sign up to a weekly email for money saving tips straight to your inbox.



Universal Credit

To make a claim for Universal Credit visit www.gov.uk/how-to-claim-universal-credit, or contact the Universal Credit Helpline on **0800 328 5644** if you cannot get online. Citizens Advice Knowsley run 'Help to Claim' to support residents to make their claim for Universal Credit. Call **0800 144 8 444** or visit www.citizensadvice.org/helpclaim



Knowsley Works

If you'd like help and support to get into employment or training, contact the Knowsley Works team on **0151 443 5010** (Huyton), **0151 443 2040** (Halewood) or **0151 443 4933** (Kirkby).



Registered Social Landlord support

If you're a tenant in Knowsley, you may be eligible for support from your housing provider. Find out more by contacting your registered social landlord directly:

Livv Housing Group – visit www.livvhousinggroup.com or call **0151 290 7000**
For Housing – email hello@forhousing.co.uk or call **0300 123 55 22**
Plus Dane Group – visit www.plusdane.co.uk or call **0800 169 2988**
Riverside Housing Association – visit www.riverside.org.uk



Support with fuel costs

Emergency support with fuel costs may be available if you have a prepayment meter and are on a means tested benefit. Visit the Council's website (www.knowsley.gov.uk) and search 'Emergency Support Scheme' to find out if you are eligible and apply. If you cannot get online, call the Council's Contact Centre on **0151 443 3200**.

If you are not on a means tested benefit but have a prepayment meter and are struggling to afford to top it up, call the Council's Contact Centre on **0151 443 3200** to see what support could be available.

If you have a credit meter and are worried about paying for your energy, you should talk to your supplier directly.



Heating support

Merseyside Fire and Rescue Service could support you if your heating is not suitable or you can't afford to heat your home. Find out more by calling **0151 296 4000**.

Knowsley Council also run a Warm Homes programme which now includes emergency repairs for boilers and central heating systems. Fuel vouchers may also be provided. To find out more, contact Simon.Rugen@knowsley.gov.uk



Looking after your mental health

A range of advice and tips to look after your mental health can be found at www.kindtoyourmind.org.uk including helping you to manage anxiety, coping with loneliness and looking after children's mental health.

There's also a 24/7 crisis line you can call if you need help and support – call **0800 051 1508**.

