

WELCOME TO THE FEBRUARY / MARCH EDITION OF CARERS NEWS

Caring for a person with a long term heart condition: My life as a carer

Written by Julie



I first met my husband when he was waiting for a heart bypass. Since then he has had pacemakers, defibrillator and ablations, you name it, and now a LVAD (Left Ventricle Assist Device), and he is currently waiting for a heart transplant.

A couple of years ago I desperately needed someone to talk to, someone who wasn't my parents or friends, as I felt guilty talking yet again about my husband. When I enquired into any kind of support groups for carers, I was surprised to

find there were no groups in Leeds specifically for carers of people with heart conditions.

It seemed all the support was geared towards the patients. It's us carers that sit everyday watching and listening to their partner waiting for any slight change, or the worrying words 'Oh I don't feel right well...'

At times you can feel very isolated caring for someone with a heart condition, but I've realised that there are other people going through very similar experiences.

So I took it upon myself, with support from Carers Leeds, to set up a support group, a place where people can sit down and chat over a coffee - without feeling guilty! And here it is...

Drop-In Café for carers of people with a heart condition

Friday 26th February
Friday 29th April
10.30am - 12pm

The drop-in coffee mornings are open to anyone who supports someone with a heart condition and are run approximately every 3 months at Carers Leeds. Please drop-in for a coffee and a chat with other carers, let's share ideas and support each other. I look forward to meeting you all!

Calling all parent carers - Max Cards are here!

From February, families of children with additional needs living in Leeds will be able to obtain a Max Card from Carers Leeds.

The Max Card is a national discount initiative for children aged 0-19yrs with special educational needs or disabilities; the scheme enables families to access over 1000 attractions nationwide either free or at a discounted rate.

The card lasts for up to 2 years and as part of Carers Leeds commitment to supporting parent carers and their families we are giving these away **FREE!**

Simply visit www.mymaxcard.co.uk to browse through lots of exciting discounts on your doorstep (or further afield!) including Jorvik Viking Centre, Eureka! and Legoland.

To get your **FREE** Max Card please contact the Parent Carer Support Worker at Carers Leeds or call the Advice Line on **0113 380 4300**.



Lyall Cookward at Eureka! making full use of his Max Card.

Including carers to improve mental health services

Leeds and York Partnerships Foundation Trust (LYPFT) provide a number of mental health and learning disability services and are keen to improve the experiences of carers.

LYPFT would like to speak to carers about your experiences, what worked well for you and what could be improved. If you have had recent

experiences of any of the mental health services and would like to be involved in developing and delivering the improvements to services, please get in touch.

To find out more or to register your interest in this work please contact Stephen Taylor on **0113 380 8913** or email stephen.taylor@carersleeds.org.uk

Leeds Autism AIM



Managed by Advonet, Leeds Autism AIM is a new service, providing advocacy, information and mentoring aimed at autistic adults with little or no funded support. The service is also there to support carers, family and friends and has supported over 350 people since January 2015. The service includes:

The Autism Hub: a weekly drop-in service at the Lovell Park Centre, in partnership with the Citizens Advice Bureau, supporting with issues such as benefits, housing, DWP employment advice, peer support, information and a range of workshops/talks.

The Information Service: offering advice by phone or email, and via the Leeds Autism Directory www.autismleeds.org.uk

Mentoring Service: specialist trained volunteers who can provide regular support to identify life goals and help overcome barriers.

For more information contact Wendy Cork on **0113 205 6532** or email leedsautismaim@leedsadvocacy.org.uk

The Relatives & Residents Association

A national charity benefiting older people in residential care, as well as their families and friends.

The Relatives & Residents Association run a helpline which offers information, comfort and support to the many family members and friends who find themselves, either having to deal with helping their loved ones make the move into a residential home or, raising concerns about the care they are already receiving.

The Relatives & Residents Association Helpline is **020 7359 8136** open Monday to Friday 9.30am – 4.30pm. Alternatively you can email: info@relres.org or visit: www.relres.org



A huge and heartfelt thank you to Markel in Leeds, for their generous donation of Christmas gifts.

These are donated by Markel staff and all lovingly wrapped by Heather White the Receptionist at Markel in Leeds. We give these gifts to our carers as an appreciation for all they do to care for their loved ones.

Markel are one of our greatest supporters not only at Christmas but all year long, and many of our coach trips and social events are down to their generous donations. We send our sincere thanks to them.



Pictured: Val Hewison and Heather White

Angie Thompson, Carer Group Coordinator organised numerous Festive Celebrations during December 2015 for carer support groups across the City, the success of these groups wouldn't have been possible without the following people and their very generous donations – Thank you!

Matthew at Peasehill House Hotel, Bernard Hopkins at Coe's Fisheries, The Management Team at the Holiday Inn in Garforth, Des McCormack at Evans Halshaw (Vauxhaul, Leeds), Anji Workman, Wendy Bairstow at Morrisons in Hunslet, Kieron Whiley at Costa Coffee, Claire Balding Management Company, Chris at Angel Inn in Morley, Zoe at Marriott Hotel, Heather Stallard at Nando's, and Valerie at Mercure.

Worried about Universal Credit?

Universal Credit is a new type of benefit designed to support people who are on a low income or out of work. It will replace six existing benefits and is currently being rolled out across the UK.

Universal Credit is being introduced in stages, it will come into effect in Leeds from 1st February 2016, however most people won't experience any change.



At the moment, Universal Credit mainly affects people who meet all of the following criteria:

- ✓ **single without children**
- ✓ **non-home owners**
- ✓ **jobseekers and newly unemployed**
- ✓ **not claiming Disability Living Allowance (DLA)**
- ✓ **not claiming Personal Independence Payments (PIP)**
- ✓ **aged between 18yrs and 60yrs**

If you're already claiming one or more of the benefits being phased out, you should carry on claiming as normal. You'll be told when you need to do anything differently. However, if your circumstances change, you may be asked to claim Universal Credit instead.

Universal Credit will replace:

- **Income-based Jobseeker's Allowance**
- **Income-related Employment and Support Allowance**
- **Income Support**
- **Child Tax Credit**
- **Working Tax Credit**
- **Housing Benefit**

For more information contact the Carers Advice Line on **0113 380 4300** or you can contact the Universal Credit Helpline directly on **0345 600 0723**.

Useful online information can be found here: www.moneyadvice.service.org.uk

NEW Carers Group

Starting Tuesday 23rd February at 10.30am until 12pm
Leeds Church Institute, 20 New Market Street, Leeds, LS1 6DG

Calling all parents, families and carers of children and young people with mental health issues, a NEW carers group is starting this February in Leeds City Centre.

For more information, directions to the venue (leedsconferencing.co.uk/find-us) or to see if this group meets your needs, call Angie at Carers Leeds on **0113 246 8338** or **07854 481 011**. We look forward to meeting you!

Liz, a parent carer, says: "While waiting for Child and Adolescent Mental Health Services (CAMHS) to assess and offer treatment to my daughter our family went through some really difficult times. I felt no-one understood or cared. Eventually I came across Carers Leeds. I had the chance to meet other carers who had often

been through similar difficulties. The staff at Carers Leeds are brilliant at pointing you in the right direction for help. Without their support there were times when I thought I wouldn't be able to carry on caring for my daughter at home."



Top Tips from West Yorkshire Police



Burglars know the price of everything and the value of nothing – that is the message being highlighted by West Yorkshire Police as part of their latest burglary campaign. Here are some Top Tips to keep your home secure:

- Keep your doors and windows locked even when you're in.
- Make your home look lived in – use timer switches if you're not home.

- Keep valuables out of view.
- Door chimes and burglar alarms will deter a burglar from entering your property.
- Restrict access to the rear of your property.

For more information about home security call 101 and ask to speak to your local Crime Prevention Officer.

What's On at Carers Leeds

Time for Us Café - Manicure and Massage

Thursday 11th February 11am - 2pm
Carers Leeds, 6-8 The Headrow, LS1 6PT

The Central College of Health and Beauty, located in the heart of Leeds, is a prestigious beauty therapy training school. Students and staff from the college will be offering:

- Mini manicures - shaping and polishing of the nails with a hand and lower arm massage.
- Shoulder and neck massage - a deep upper back, neck and shoulder massage to ease away tension.

Please contact Carers Leeds on **0113 246 8338** to let us know if you would like to attend, this will help us to provide enough therapists from the college and prepare lunch.



Time for Us Café - The Japanese art of Origami

Thursday 10th March 11am - 2pm
Carers Leeds, 6-8 The Headrow LS1 6PT



Ever tried making an Origami gift box? Come along and give it a go!

The Time for Us Café will be hosting a demonstration and craft session of Origami, the Japanese art of paper folding. All materials will be supplied.

Feel free to drop-in on the day, however if you could let us know you are attending this would be helpful in order to plan and prepare lunch. Please call Carers Leeds on **0113 246 8338**.

Carer Support at the Autism Hub

Last Tuesday of the month 5pm – 6.30pm
Lovell Park Centre, Wintoun Street, LS7 1DA

Carers Leeds, in partnership with Leeds Autism AIM, is providing a new support group for carers. To find out more about AIM and the Autism Hub, see page 2.

The autism carer support group will provide practical advice and information in a friendly, supportive environment. Carers will have the opportunity to meet others with

similar experiences and share coping strategies and information. A Carer Support Worker from Carers Leeds will be present at the group and access to the Citizens Advice Bureau services based at the Lovell Park Centre will also be available. For more information please contact the Carers Advice Line on **0113 380 4300** or the Autism Hub on **0113 2440 606**.

Wellbeing Sessions

Friday 18th March
Monday 28th March



Wellbeing Sessions are designed to give health benefits guaranteed to melt away your stress and tension.

Treatments are just £5 per session lasting 30 minutes. Carers can book up to 2 sessions per year.

Call **0113 246 8338** to book your place.

Dementia Friends information sessions at Carers Leeds



Dementia Friends is an opportunity to learn more about what it's like to live with dementia and the small ways you can help.

Each information session lasts around one hour. You will learn more about dementia and how you can help to create dementia friendly communities.

Dementia Friends is taking place at Carers Leeds on:

- Monday 22nd February 1.30pm - 2.30pm
- Tuesday 29th March 2.00pm - 3.00pm
- Thursday 28th April 5.30pm - 6.30pm

We welcome anyone interested in learning more about dementia, including carers, family, friends and professionals. Booking is essential, please call **0113 246 8338** or for more information speak to Nikki Pattinson.

What's On in Leeds

Webwise

Thursday 11th February from 10:30am until 12:30pm

A short course for people with learning difficulties who want to stay safe online. The training is free for people who live in Leeds. For more information or to book your place please contact Sarah Wheatley at Connect in the North on **0113 270 3233** or email sarah@citn.org.uk

Silver Surfers

55 or over? Baffled by computers, smart phones or the Internet?

Age UK provides technology courses across Leeds. All courses run for six sessions which are around two-and-a-half hours each. All courses are taught at a gentle pace and there is no pressure or exam at the end. There is always time to ask questions or go over things again. Call Age UK on **0113 389 3000** for more information or to sign up for a Silver Surfers course near you!

Sunshine and Smiles

Down Syndrome Awareness Week 18th - 24th March 2016

Sunshine and Smiles is a support network in Leeds for children and young people who have Down Syndrome and their families, by providing a range of fun and therapeutic activities in addition to support and befriending to parents. There will be a host of activities and fun days during Down Syndrome Awareness week, for more information please contact **0113 226 8457** or visit www.sunshineandsmiles.org.uk

Living with Sight Loss

Six day course starting Friday 1st April
One day courses starting from Tuesday 26th April



age-related macular degeneration



diabetic retinopathy



glaucoma



cataract

Living with Sight Loss is designed for anyone affected by visual impairment including friends and family members. Provided by Leeds Vision Consortium, part of Action for Blind People, the courses give the opportunity to discuss the challenges sight loss presents, such as: getting out and making the most of your leisure time, practical solutions to overcome challenges to everyday tasks, and using technology. For more information please contact **0113 386 2888**.

Memory Drop-in Service

On the first Wednesday of every month from 10.30am until 12.30pm



Leeds Central Library welcomes you to a monthly, informal drop-in service for people with memory problems, or people with dementia, their carers, or anyone who would like more information. The drop-in service provides a friendly environment to meet other people and share experiences. The sessions provide an opportunity to talk to professionals about any information and support needs you may have. The sessions are held at Leeds Central Library, for more information call **0113 247 6016**.

Purple Day

Awareness of Epilepsy
26th March 2016

Epilepsy is the most common serious brain disorder worldwide with no age, racial, social class, national or geographic boundaries. Purple Day was created by a young Canadian girl called Cassidy Megan who was diagnosed with the condition as a child. To drive more positive awareness of the condition, Cassidy created the themed day.

Watch out for a host of purple-themed events taking place across the UK including local landmarks turning purple in honour of the day. To find out where events are taking place in Yorkshire, or to organise your own, visit: www.purpleday.org/events

Feature Article: Online support available to carers



Carers Leeds host a number of support groups across the city giving carers the opportunity to talk at ease and gain support from those with similar experiences. As times are changing, we now live in a digital orientated world, but are we really taking advantage of the online support also available to us as carers?

Facebook kept me sane!

Written by Steph Ward, Carer Support Worker at Carers Leeds and parent carer

I joined Facebook around 2008 and at that time my newsfeed was a sea of smiling faces, photos of people's dinner, and the occasional political rant. Facebook was simply a distraction during a boring lunch break, and had it suddenly disappeared, my life would really have been no different.

However in 2009 my life changed when I became the mum of a child with complex health needs. Our son was diagnosed with a rare breathing condition, had a tracheostomy and was on a ventilator 24hrs a day, alongside many other issues. We felt our lives had been turned upside down. We didn't know anyone else with his range of complexities and felt increasingly isolated. As we spent his first 18 months going in and out of hospital, suddenly Facebook took on a whole new role.

Trawling through Facebook late one night I found an American group for parents of children with a tracheostomy. Suddenly I had found people like us, even found British parents in the group and began to share information, experiences and support one another.

The group became a lifeline - a place to talk, support each other and most of all connect with people who finally 'got it'. A place to help us through the hard times, but also celebrate even the smallest amounts of progress.

With other British parents, I decided to set up a UK Facebook group, as whilst some of the issues were the same for American parents, the whole health system was different. Tracheostomy UK Support (TrUKS) began with just 8 people, and has since grown to 830 members. We share information on equipment, new diagnosis and are there for parents now entering this scary world. People I'd never met suddenly became the closest of friends.

Our son had major surgery last year to remove his tracheostomy. It was such a stressful time but we had so much support from the group, when we knew it had been a success, they were the first people we told.

I'm still involved in the group giving support to other families, but also asking for support at times. It still feels like a calm oasis when things are tough.

Online communities provide information and support, and a valuable connection with others sharing similar experiences, available at any time of the day or night.

www.carersuk.org

Useful hints and tips on health concerns, disability benefits, social chit-chat as well as fun and games.

makingcontact.org

Being the parent of a disabled child can be very isolating and lead to stresses and strains on individuals within a family. At Family Connect you can share your experiences with others and get support too.

www.stroke.org.uk

TalkStroke is a place where you can meet other people affected by stroke, share stories and experiences, find out what has worked for others and provide each other with support and information.

www.parkinsons.org.uk

People with Parkinson's, carers, friends and family can share experiences, ask questions or just chat.

www.alzheimers.org.uk

Talking Point is a helpful online community where anyone who is affected by dementia can receive valuable support. On the forum you can: ask for advice, read other people's stories, offload your concerns about dementia, share helpful information.

Hello! From Jo and Lorraine



As Carer Support Workers you will find us at St James Hospital and Leeds General Infirmary. We are there to support carers who look after someone with dementia, and help you during

hospital admission. We are here to support you through what can be a difficult and stressful time, whether that is helping you to understand the hospital discharge process, liaising with staff or providing a listening ear to just talk things through. We also attend care planning meetings and dementia cafés. Between us, we have years of experience working in hospitals and in caring for people living with dementia. We look forward to meeting you all at Carers Leeds events and hope that this Spring finds you all healthy and well!

Hello! From Janice, Dawn and Fiona



Some of you will know us from our previous Carer Support roles at the Alzheimer's Society. After working in partnership with Carers Leeds for some time, we have finally relocated to join the team. In some ways, it feels like

coming home! Between us, we have over 30 years experience of supporting carers of people with dementia and we welcome carers – both old and new to the service. We can offer help with benefits, support to access services, social activities, respite, carer training and much more. The emotional side of caring for someone with dementia can sometimes be exhausting and hard to cope with. In addition to looking at the practical aspects of caring for someone, we are here to listen and support you through those difficult times.

Hello my name is Jill



I joined Carers Leeds at the end of August as a Carer Engagement Worker. My post is funded by Leeds Community Healthcare (LCH) NHS Trust and is for 12 months. Over

the year I will be working with carers to help the LCH teams get a better understanding of carers' needs and how support for carers can be improved. There will be a particular focus on carer experience within certain clinical services and I will be working with those whose views and ideas are often not heard. So please look out for opportunities to get involved with my work in the coming months or if you are interested to know more about what I am doing please contact me at the Carers Leeds office on **0113 246 8338** or e-mail: **jill.morris@carersleeds.org.uk**

Christmas Get Together

In December, the South Leeds family and friends mental health support group met for Christmas Dinner. Members contributed to Secret Santa, thoroughly enjoyed their meal and a much needed break.

The group would like to thank Carers Leeds for their continued support and generosity to enable this to happen.

"We would like to extend the invitation to other carers who may need support to come along and attend the group."

Meetings take place on the third Wednesday of the month at Parkside Community Health Centre, Dewsbury Road.



Get involved in Carers Leeds

The Carers Leeds Focus and Advisory Group is made up of carers who take an interest in how the Carers Leeds service is developed and delivered.

We're looking for new members to join the group that meets once every 2 months. All members have caring responsibilities – all contributions are welcomed and valued.

Please contact Helena on **0113 246 8338** or email **helena.bladon@carersleeds.org.uk**

From the Postbag

Sharing useful information, stories and experiences.

I want to hear from YOU! Have you come across a new, useful or friendly service that other carers may benefit from, or perhaps you want to share your story and experiences of being a carer? **This page is for YOU!** Contact Rachel Moore, Newsletter Editor via post or email: rachel.moore@carersleeds.org.uk

This month our readers want everyone to know about...

Memory Calendar



Successfully trialled by the Derbyshire Alzheimer's Society in 2014, the Memory Calendar shows

just one day at a time with space to enter what is important on a particular day (events, appointments, anniversaries, etc). Place in a prominent position, it is self supporting, can be laid flat, or even carried in a handbag.

For more information visit:
www.cap-ox.com
 email: sales@cap-ox.com
 or telephone **01865 723404**.

3Rings Plug

Imagine just by mum making a cup of tea or dad turning on the TV to watch his favourite programme, that the whole family can know that their loved ones are OK each day or alerted if things may not be. That's what the 3Rings Plug does. No Internet is needed for the Plug as it has its own built in mobile phone. Simply plug in and connect an appliance and the 3Rings Service alerts are sent directly to the family's smartphones, tablets or PCs. Price from £79 with a monthly subscription.

For more information visit: www.3rings.co.uk, email info@3rings.co.uk or telephone **0161 731 0081**.

Blue Assist



Have you heard of Blue Assist? It's a little blue card, or an app for your phone, that enables

you to display a message, whether that's asking for directions, an item in a shop or help getting on the train. This is a useful communication method for people who are deaf, suffer with anxiety or other mental health conditions, or who have dementia or a learning difficulty, or lots of other reasons that make it harder to communicate. For more information visit: www.blueassistuk.org.uk or telephone **01273 906 221**.

If you are able to receive the newsletter via email, if you are no longer caring, or if you have received more than one copy at the same address, please let us know.

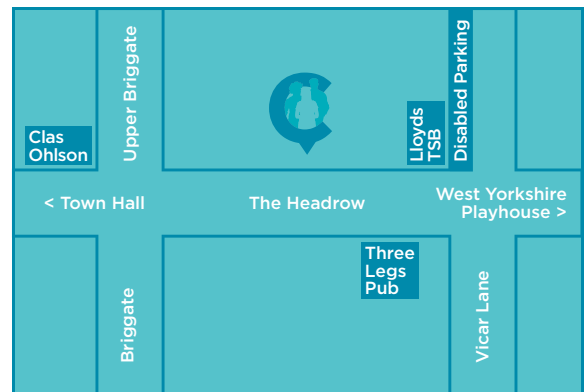
Contact Details

- **Carers Advice Line 0113 380 4300**
(9 am – 4.30 pm, Monday - Friday)
- **Drop-in to Carers Leeds City Centre office**
(10 am – 3.30 pm, Monday - Friday)
- **Email: info@carersleeds.org.uk**
- Message via the website, Facebook or Twitter

For support for carers aged 5-17, contact Willow Young Carers on 0113 262 2851

6/8 The Headrow, Leeds, LS1 6PT
Admin telephone number: 0113 246 8338

Carers News is also available in large print and on audio tape or CD.
 Please contact Valerie Banks at Carers Leeds on 0113 246 8338 to request your copy.



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