



Welcome from Jayne Price, our Forum Chairperson

Hello, and happy Spring! Welcome to our latest newsletter and it's nice having milder weather along with lighter evenings. I do like this time of year with the Spring flowers and budding leaves brightening up the greyness of a couple of months ago.

At the Forum, we're still as busy. Last month we held our second AGM. This was later than originally planned due to many of us on the Management Committee experiencing ill health during last year and I expressed that I would rather everyone individually take their time to feel better rather than rush into things. We eventually 'got there' and I must thank everyone concerned, especially, Vickie, our Development/Administration lady who has worked since she started, especially when she managed to get the Annual Report together at very short notice.

The work continues, which is pleasurable to do so that we can represent your voice and let you know what is going on. With being part of The Borough That Cares network, we, along with our strategic partners, are currently working on a new RMBC Carers' Strategy, which is due to be renewed this year. We welcome any carer(s) to become involved especially if they feel they are under represented and that they are not listened to. Please get in touch with me on jayne@rotherhamcarersforum.org.uk if you are interested in this voluntary but rewarding role.

Also, Carers' Week 2025 is just round the corner, that is, from 9th to 15th June. The theme for Carers Week 2025 is '**Caring About Equality**' highlighting the inequalities faced by unpaid carers, including a greater risk of poverty, social isolation, poor mental and physical health. Far too often, carers of all-ages miss out on opportunities in their education, careers, or personal lives, just because of their caring role.

So far, the Rotherham events being planned for 'Carers Week' are out market information stalls on Tuesday 10th, information stalls in the foyer of Rotherham General Hospital on Wednesday 11th and our own Carers' Week event/informal monthly meeting on Thursday 12th at the Town Hall between 12 noon and 2pm. Further information will follow on our Rotherham Carers Forum - Community Page on Facebook as we get to know it along with information being posted on the News page of our website www.rotherhamcarersforum.org.uk

Wishing you all a happy and healthy early summer and please look out for our next newsletter edition around Rotherham show time.

Jayne

Jaynes Blog...when it comes time to move on

If you have been reading my blog about my daughter moving into supported living accommodation, I am glad to say this is the final part.

You may recall that we were almost there just before Christmas. The week before Christmas, Alana and I really went to town in partying and going to places she really likes. On the Monday we did Wath Panto, on Tuesday we went to a party with the day centre, on the Wednesday night and Thursday night we went to two more parties' courtesy of her social nights and then it was her favourite, Disney on Ice on Friday. I calculated that I would have enough time to do the wrapping and the food shopping.

The week of Christmas, I began to feel very lethargic as though I couldn't be bothered which upset me. Christmas Eve came and it was a case of if it's done it's done, that it's only one day of the year. On Christmas Day, I overslept until 11 am which again bothered me because it was Alana's last Christmas living with us. The presents were opened, and I'd planned a 'picky' Small lunch, which my husband took over and it was one less thing for me to do. I fell asleep again at 3 pm and woke at 9 pm with one leg puffier and redder than the other. Alarm bells started ringing and I took myself down to A&E At 2 am on Boxing Day morning (Luckily, I had been too tired to drink any alcohol). One week and one day later, I managed to get myself discharged from hospital which blew any plans for New Year out of the window. My husband, bless him, tried to look after Alana but he is her stepdad, and I felt it was better for him to contact social services on the Monday between the two big days. Thankfully, Rotherham social services acted straight away and gave us two emergency weeks for Alana to go into respite which she was familiar with. In a strange way, this could have prepared her for well for what was going to come. My leg was infected with a diabetic ulcer which, in the worst-case scenario, was going to result in me losing one of my big toes.

This experience was also a wakeup call as to why it had become good sense for Alana to try moving onto the next chapter of her life. When I had settled back at home following hospital, we had a full team meeting with everyone concerned with the move. A new date of 10th of February was agreed for the move. Strangely, my experience had prepared me for what was to come. I continued to talk to Alana about what was going to happen and started to show her photos whilst reassuring her.



As the day came, Alana was wary of entering her new home but as soon as she saw her bedroom that was full of her favourite items which had strangely disappeared from home during the previous weeks, she went up to her new computer, turned it on and recognised that the icons were the same as the one she has at "mummy's house". The staff were lovely and spent time talking to Alana.

One thing that I had done off my own back was to draft out a 'moving in document' filled with nitty gritty pieces of 'what makes Alana tick' Information. This document ended up as a 14-page document. The people responsible for caring for Alana have since told me that this has been invaluable. It has been acknowledged since the move that my husband and I had worked very hard prior to the move which has made it so successful. When it was time for me to go, Alana didn't bat an eyelid but simply raised her cheek when I went to kiss her.

It turned out she had the time of her life for the rest of her week, and I have received a collection of photos with her beaming away without a care! It made it much easier for me knowing how happy she was, and the transition has been easier for both of us. In fact, on a few occasions when I have met up with her, she has been reluctant to come back with me! She was ready for the move!

On a practical note, it has meant changing doctors and chemists. She remains at the same dentist but contact details have needed to be changed with everyone. There were a few hiccups like the support workers not realising we'd set it up so that they had to withdraw money to pay the day centre. It was things like this that you often take for granted that somebody else should know the process.

We had an issue with Alana getting on transport, i.e. a minibus to go backwards and forwards to the day centre. I was told about it but I do confess that it was a relief not to have to deal with it. The matter has been resolved, and Alana is now happy to go to the day centre. I am still going through the legal process with The Deputyship. This is a long process and must be precise due to it being a serious legal issue. I've had time for hospital appointments which have come in an abundance following my hospital stay. I'm now able to do things of importance for my son like being there to watch him complete the Manchester Marathon last weekend, I can still do things with Alana. She has had two weekends with us as her favourite holiday destination, that is, Haven at Cleethorpes. I will be picking her up on Saturday to take her to the cinema to see her favourite Disney film at the moment, Aladdin. She gets taken to her social nights without having to depend that I am up for it. Unfortunately, I have had to give Gateway a miss with her when my foot was in a bandage but now she has the opportunity to be with her social friends twice a week, whatever happens.

Let's just say, she tolerates her housemate, but she has her own space to chill out in. The mobility car has gone with her so that the staff are able to take her out when she is not at her day centre.

Overall, it has been for Alana a surprisingly smooth and mostly trouble-free move which everybody is over the moon with.

Meet the team

MEET ANGIE LINDSAY- MEMBER OF OUR MANAGEMENT TEAM



**HI, MY NAME IS ANGIE LINDSAY AND I AM A MEMBER OF THE ROTHERHAM CARERS FORUM AND I VOLUNTEER ON THE MANAGEMENT COMMITTEE.
HERE'S A LITTLE ABOUT ME!**

I was born in Rotherham, I was raised in Wickersley with my younger brother, we are very close and he is a source of support for us.

I care for my 46 year old daughter who has physical and learning difficulties, recently we discovered she had also been infected with a virus during a blood transfusion in the 1970's. She has a twin brother and two younger sisters.

Again, my family support us a great deal.

I began my working life in an office, left to raise my family, then returned to office work. It wasn't for me, so I obtained work in a care home then later as a community carer – I really loved the work but it wouldn't pay my mortgage when I divorced. I went to Rotherham college for 3 years then Sheffield Hallam University for 3 years and qualified as a Social Worker, I worked in Adult Services in that role from 2001, and then I worked as a Development Officer, training Social Work Students.

I left full time work after a medical issue of my own in 2017, and I was really struggling in my unpaid carer role looking after my daughter and my mum who had Dementia. I had already been attuned as a Reiki Practitioner in 2014, I had trained for a year as a Clinical Hypnotherapist qualifying in 2016, then I opened my own business in April 2017, I had a therapy room in Wath on Dearne until August 2023. I went back to Doncaster College in 2019 to 2020 training in Level 3 Complementary Therapies and I work now fully mobile in people's own homes providing Reiki, Massage, Reflexology and Hypnotherapy.

I became a member of Rotherham Carers Forum in 2017, and I volunteered for RCF providing health and wellbeing workshops in 2018 – 2019. I volunteered as Chairperson for a short time, but found it difficult to commit due to running my own business.

My mum is now in her heavenly home and I carry on knitting and sewing in my spare time just the way she taught me. I also love reading – I've always got my kindle with me!

Please read on for a special article this month written by Angie...

ANGIE'S STORYINFECTED BLOOD SCANDAL

On the 18 th May 1978 I gave birth to undiagnosed, premature twins in Jessops Wing Hospital, Sheffield. Being only 28½ weeks gestation, they were incredibly small, the first a boy weighing 2lb 5oz and the second a girl weighing 1lb 14oz. Having to share a respirator – changed over every two hours as one twin got too tired to breathe so it was switched over - their life was in the balance. Initially they were in separate incubators in the top intensive care room in the special baby care unit, moving down the ward as they grew and became stronger.

At around 4 weeks old they were becoming anaemic and the doctor asked me to roll up my sleeve to give blood as one twin needed a blood transfusion – it was explained to me that as they grew and needed more blood, their bodies were too premature to make their own. A couple of days later, I was asked to roll up my sleeve and give blood again as the other twin needed blood. I remember standing by the side of their incubators watching the blood going into a vein at the side of their heads – it was the largest vein the doctor could find – it was a struggle, the needles they had weren't small enough for my tiny premature babies.

When the twins were 8 weeks old and still in the baby care unit, I was told that my daughters' stomach had haemorrhaged, she was moved back up to the top intensive care room as she 'needed a bit more support right now' – I believed this was due to the one respirator being in that particular room. A few days later I was shocked to find her brother had been moved into the top intensive care room, but it was explained to me that neither twin had increased in weight for a few days so they put their incubators together to help them thrive.

At 10 weeks old, my son came home and 6 weeks later – at 16 weeks old my daughter also came home. She was very underweight at around 5lb, but the hospital let her come home early as she wasn't gaining weight at the normal rate and they assumed she was pining again for her twin. Whilst my son thrived, my daughter was born with a very rare genetic syndrome – unfortunately not diagnosed until she was almost 6 years old that causes a mosaic of health issues. She had experienced many health issues, and I assumed this was part of her syndrome as little information was known about it, but the hardest diagnosis to hear was her diagnosis of having a moderate learning disability at 8 years old although we know now the syndrome does not cause this.

Life continues as it does, family grew and left home, my daughter remained with me as her main carer and mum, we were plodding along together as you do until last June 2024 when the whole of our world turned upside down. My son contacted me from his home in Devon asking if he and his sister had been given blood transfusions when they were babies as he seemed to remember me saying they had. He explained that he had seen online that the Infected Blood Inquiry report chaired by Sir Brian Langstaff was due to be released on the 20 th May 2024 and suggested he and his sister have Hepatitis C tests just in case. I always assumed they had been given my blood but agreed to help his sister apply for a test kit anyway – thinking it will allay any fears that either twin had been infected, after all – neither were ill and surely the NHS would have informed them that they could be at risk? Imagine our shock a couple of weeks later to find my daughter was infected with Hepatitis C – my beautiful, brave, strong warrior who had overcome everything life had thrown at her for 46 years, now has an infection that has probably caused lasting damage to her and we never knew.

Her brother's result thankfully was negative but for him – the result was bitter sweet. I sprang into action, within 2 days the Hepatitis nurse had visited, taken bloods to ascertain the particular strain, undertaken a liver scan only to find moderate to severe liver damage, and promised to return a week later with the correct medication that will need to be taken for 12 weeks. I watched the video of Sir Brian Langstaff delivering his speech about the Infected Blood Scandal where every politician, health minister, health authority knew the blood given in the 1970's to mid-1990's was probably infected with either/or Hepatitis B, Hepatitis C or HIV but given to patients anyway, read every newspaper report, watched every documentary, every newsreel of the courageous people fighting for justice over the past 30 years, researched hundreds of research articles about the effects of Hepatitis C, filled in forms, learned that 2 people a week were dying following transfusions, scoured Government websites – it was relentless, all whilst supporting my daughter with the medication, stigma, fear, endless questions of why me, where is it from, will it go away. I was exhausted but I had been told I needed to find the evidence of blood transfusion/s, she couldn't possibly have caught it any other way. I applied for her medical records from 2 hospitals and her GP, it was a complicated process, each needing different things, each had their own policies.

The hospital where she was born informed me they had destroyed her records when she was 25 years old as per the NHS Code of Practice Retention Schedule July 2016. The hospital where she had numerous operations as a child sent me a file with over 280 pages of medical information which was very emotional to read.

The GP took a week over their own 28-day policy to disclose information – 5 weeks we waited, I was frustrated but bingo –there it was, the date her stomach haemorrhaged she was given a blood transfusion, the same day, clearly recorded on her GP notes. I hadn't been informed they had given her blood from a blood bank. The 'bit more support' she was given at 8 weeks old was Hepatitis C infected blood which had replicated in her tiny body until detection at age 46, silently causing irreparable damage to her internal organs.

But it got me thinking – if I didn't know as my daughters' mum and carer, how many other people with physical and/or learning disabilities have had transfusions and are unaware? I needed to do some more research.

I contacted the Hepatitis C Trust first of all, they informed me they have never ran a campaign purely for Carers and people with learning disabilities, they do lots of outreach work and support for those infected but their resources are stretched. However, they did agree to design a couple of posters specifically aimed at Carers and checked with me that they were appropriate for my target audience. They also gave me lots of support around my daughters' application for compensation which is in itself a minefield.

I contacted Rotherham Advertiser, we had a visit from a wonderful reporter called Gareth Dennison who wrote an amazing front page piece that was published on Thursday July 4 th 2024 highlighting how a local family have been impacted by the Infected Blood Scandal and urging people who think they or a loved one has had a blood transfusion to get tested. When Gareth asked my daughter how it made her feel, she reported 'feeling dirty' and that absolutely broke me.

However, I pressed on and wrote to our MP John Healey to ask for an appointment to discuss the issue of carers and those with disabilities and learning disabilities, and in due course I did meet with John who gave me lots of support for which I'm very grateful. I forwarded the posters from the Hepatitis C Trust to his office and they were duly sent out to lots of organisations in Rotherham, urging people to get tested if they thought they were at risk.

I raised our story with Rotherham Carers Forum who have given me lots of moral support, and helped to raise awareness at strategic meetings, online and at the RCF meetings – thank you for listening, caring and promoting our cause.

Right now, my daughter is testing negative. She's had ultrasound scans and will need one every six months for the rest of her life as well as blood tests, because the risk of her developing liver cancer is significantly increased. She's coping really well – she's almost stopped drinking alcohol, walks daily and eats healthily, mentally – the Hepatitis nurse described her as a ray of sunshine. As her mum, I had counselling, I've just been discharged but there are still times when I wake up in a panic, or I wake thinking my world is good, then realise it's not.

My mantra? The guilt is theirs; the grief is ours.

Please, please get yourself or your cared for person tested if you had a blood transfusion prior to 1996. It's a silent killer and you don't know it's there until the damage is done.

Our battle for recompense continues, my work is not yet done.



HAD A BLOOD TRANSFUSION BEFORE 1996?

GET TESTED FOR HEPATITIS C

If the person you care for had a blood transfusion, blood products, or an organ or tissue transplant in the UK before 1996, there is a chance they may have been exposed to hepatitis C.

Speak to your GP about testing or order a free at-home test kit today.



Test at home

Scan QR Code
or visit
hepctest.nhs.uk



For support and information about hepatitis C, visit The Hepatitis C Trust website:
hepctrust.org.uk

Helpline details:

020 7089 6221 (visit our website for opening hours)

helpline@hepctrust.org.uk

Charity registration numbers: Scotland SC039954, England and Wales 1104279, Company number: 05069924

Support and Information

Do you need emotional support, information or have a question about hepatitis C?

Our helpline team is here for you. All our helpline staff and volunteers have personal experience of hepatitis C diagnosis and treatment.

Call: 020 7089 6221

Open Monday to Friday, 10.30 am to 4.30 pm

Email: helpline@hepctrust.org.uk

Carers Week is an annual campaign to raise awareness of caring, highlight the challenges unpaid carers face and recognise the contribution they make to families and communities throughout the UK. It also helps people who don't think of themselves as having caring responsibilities to identify as carers and access much-needed support.

Carers UK, in partnership with supporting charities, has announced the theme for Carers Week 2025, running from 9th-16th June.

This year's campaign will focus on 'Caring About Equality', highlighting the disparities and disadvantages faced by unpaid carers across the UK and calling for a fairer society where they have access to greater support.

"June 9th - 15th will focus on the theme of 'Caring About Equality' highlighting the disparities and disadvantages faced by unpaid carers in the uk. the week aims to raise awareness of the challenges carers face and call for a fairer society where they are truly valued, recognised and supported,

Credit: Carers uk - <https://www.carersuk.org/>

We will be taking part in Carers Week by being in the following locations:

So far, the Rotherham events being planned for 'Carers Week' are outside market information stalls on Tuesday 10th of June. You will be able to find us in the centre of town with our Care group partners on information stalls within the Tuesday market. Please come along and say hello.

On Wednesday the 11th, we will be in the foyer at Rotherham General Hospital with our Care group partners. If you are there, please come along and say hello.

On the Thursday 12th, it is time for our monthly meeting at Rotherham Townhall (The Crofts). We would love you to come along. If you are, then please let us know for catering purposes by filling in your details on this link below

<https://www.rotherhamcarersforum.org.uk/joinanevent>

For further details, please keep your eye on our website or social media

<https://www.rotherhamcarersforum.org.uk/>

Our Monthly Meet-ups

We meet monthly at Rotherham Town Hall to share experiences, learn from each other and enjoy some light refreshments.

We often have guest speakers who provide useful information for Carers.

It has been a quiet start to the year, with many members overcoming difficult times, illness, and change in circumstances. We have been there for each other sharing updates and offering support.

We still met up during January and February and chatted about our Christmas and New Year, swapping stories and having a good old giggle.

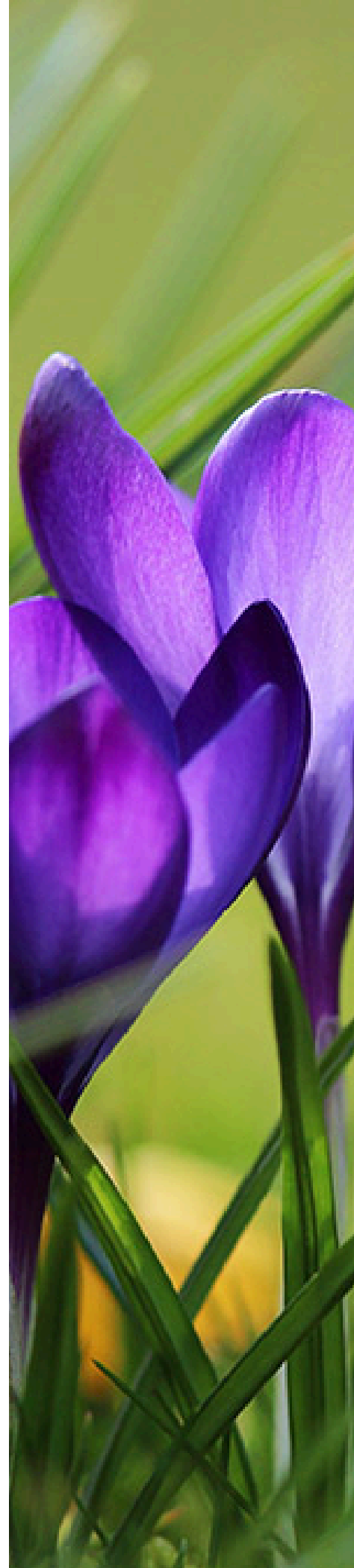
March saw the Forum hold it's second Annual General Meeting (AGM) more about that later.

For the month's ahead we have several sessions planned including a crocheting session, a session with RMBC regarding the Carers strategy, art session and an update with our local Health Watch.

So do keep an eye out for emails and social media updates which will give you all the details and how to book to join us

<https://www.rotherhamcarersforum.org.uk/joinanevent>

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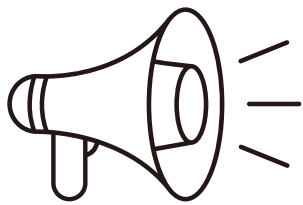
ROTHERHAM CARERS FORUM - ANNUAL GENERAL MEETING

In March we were able to have our second AGM and we would like to thank those that came along. These included members and people with an interest in what we do, Including representatives from other Care Groups, other voluntary organisations who have some common interest in us and representatives from the local authority and Health services. We eventually 'got there' and I must thank everyone concerned, especially Vickie, our Development/Administration lady, who has managed to get the Annual Report together at very short notice that came along.

It was good being able to present information on what we have delivered during the first and second AGM Along with tasters Of what we have planned for this future year. We were able to offer a late lunch to those who came and it gave everyone a relaxed opportunity to network and chat about how Local family and friends carers' lives can be improved.

I mentioned during my opening speech that I would like us to concentrate on our sustainability, including building a stronger management committee. If you are passionate about improving carers lives in Rotherham and would like to join us, please let me know by emailing jayne@rotherhamcarersforum.org.uk





UPCOMING EVENTS

OUR NEXT MEET-UP THURSDAY

8th may 12 NOON - 2 PM

ROTHERHAM TOWN HALL

Committee room 1



Light lunch provided

MAY 8TH

THIS MONTH WE WILL BE JOINED BY KATY LEWIS FROM RMBC WHO WILL GIVING US AN UPDATE ON THE CARERS STRATEGY AND ASKING FOR YOUR THOUGHTS AND FEEDBACK



June - to be confirmed

JULY 10TH -

THIS MONTH JOIN TO US TO HEAR ANDREA FROM HEALTHWATCH ROTTERHAM GIVE US AN UPDATE OF WHAT THEY HAVE ACHIEVED OVER THE PAST SIX MONTHS AND TO HAVE YOUR SAY ON HOW THE HEALTH SERVICES HAVE DEALT WITH YOU, HOW YOU FEEL ABOUT THEM AND WHAT YOU THINK COULD BE DONE TO IMPROVE THEM



NO MEET-UP DURING AUGUST

TO BOOK PLEASE CLICK THE LINK BELOW

<https://www.rotherhamcarersforum.org.uk/joinanevent>

YOU CAN FIND ALL OUR EVENTS ON OUR WEBISTE AND SOCIAL MEDIA PLATFORMS

SUPPORTING OUR FUNDRAISING

Please consider supporting our fundraising which provides our meet-ups, events and provides information by purchasing lottery tickets



<https://www.rotherhamcommunitylottery.co.uk/support/rotherham-carers-forum>



- Help give our fundraising a boost
- Tickets cost just £1 a week
- Win up to £25,000



EASY FUNDRAISING

HOW IT WORKS

Easyfundraising turns your daily shopping into every day magic!

Easyfundraising partners with over 8,000 brands who will donate part of what you spend to Rotherham Carers Forum if you have chosen us to be the good cause and it won't cost you any extra.

The cost is covered by the brand.

Brands pay easyfundraising commission because when you start your shop from the easyfundraising website or app, the brands can see that Rotherham Carers Forum has been allocated to them as a good cause to donate to. If you make a purchase, a commission is generated, and easyfundraising turns that into a donation - magic!

IT COSTS YOU NOTHING. YOU CAN SIGN UP HERE

[HTTPS://WWW.EASYFUNDRAISING.ORG.UK/CREATE-AN-ACCOUNT/](https://www.easyfundraising.org.uk/create-an-account/)



Poetry Page - This edition's poem has been chosen by our chair Jayne.
Enjoy...

**'Who cares for that carer?' I hear a man say
'Her day blends with night and then night
becomes day.
'The cooking, the cleaning, the hospital trips,
The changing, the bathing, wiping food from
his lips,
The meltdowns, the tears... so hard to endure,
What keeps her from walking straight out of
that door?
I'll tell you what stops me from leaving each
day
And what gets me through when I don't want to
stay
It begins with an 'L' and ends with an 'E',
It's a power, a force, emanating from me,
An empathetic heart, a gift from above,
I do this, my friend, in the name of LOVE.**

Poem courtesy of Carers Uk
<https://www.carersuk.org/>



Here at RCF we passionately believe that 'your voice matters' please email admin@rotherhamcarersforum.org.uk with your ideas for future events you would like to see, guest speaker suggestions or articles for the newsletter.

THE GALLERY - A FEW PICS FROM EVENTS & MEETINGS



Crotching session - April 2025

Our beautiful Alana celebrating her birthday with us



Deep in discussion - wellbeing session



Start of our worry worm collection

OUR SOCIALS & CONTACTS:
please like, follow & share



ROTHERHAM CARERS FORUM



@ROTHCARERSFORUM.BSKY.SOCIAL



WWW.ROTHERHAMCARERSFORUM.ORG.UK



admin@rotherhamcarersforum.co.uk



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