Over A Brew Session

25 September 2024

Carers

OVER A BREW

CURATORS OF CHANGE

directors of
adass
adult social services
eastern region
connecting innovating improving

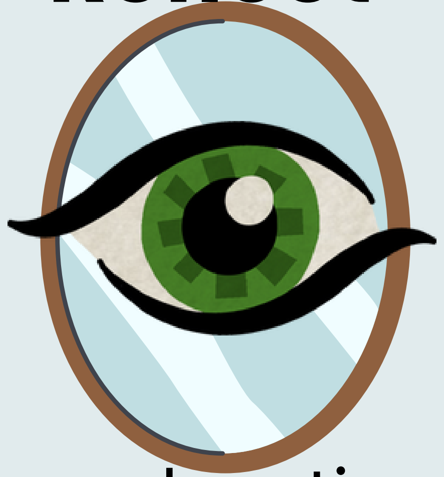
[redacted]

Guide

Grab a brew

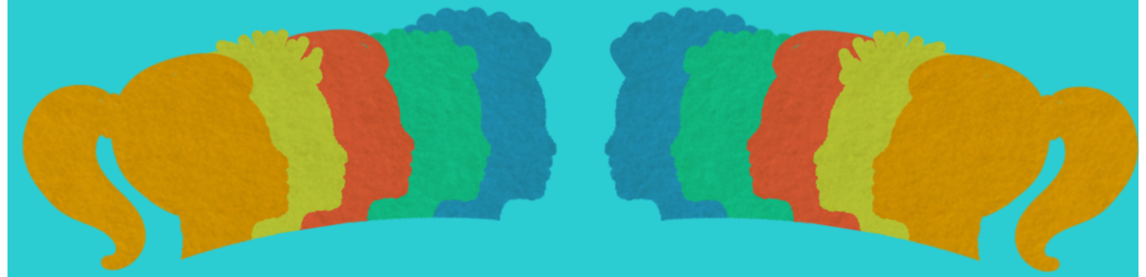
Once you have your brew, ask someone to be the timer

Reflect



Each person has time to think about the questions for ONE minute

Have your say



Each take it in turns to say your response
(TWO mins each)

Use the rest of the time to reflect on what's been said
(no fixing)

Still got some time?

Talk about:
What's not been said?
What are your lasting thoughts?

INFUSED WITH THE CAMERADOS PRINCIPLES

MIX WITH **PEOPLE** WHO ARE **NOT** LIKE **YOU**

ASK SOMEONE WHO IS **STRUGGLING** TO HELP **YOU**

NO FIXING - JUST BE **ALONGSIDE** ONE ANOTHER

IT'S OK TO **DISAGREE RESPECTFULLY**

IT'S OKAY TO BE **A BIT RUBBISH** SOMETIMES

TO **BE SILLY** IS TO **BE HUMAN**

Introduction

Around 35 people attended the session to share ideas, insights and views… Over a Brew

This Over A Brew was an invitation to listen to the experiences of family carers, who are not in paid caring roles, but provide care and support to their loved ones.

We introduced the session with a couple of minutes of a video of 2 carers talking about language. The whole video is on the Over A Brew web page. This video was created as part of other regional work on carers issues. https://adasseast.org.uk/?s=language

The session opened with Jacqui sharing her poem about the day her son was born, the impact it had on her, the realization that her life as a mum was to be life as a 'carer'. The impact in terms of language and how we label people as a carer, rather than recognising their status as mum is significant to people, and this is something that is talked about in the video referenced above.

We played a second video that of carers sharing their experiences of being carers more broadly, including reflections from Isaac of what it can feel like to be dependent on family members being in a caring role with them. The video can be found here: https://adasseast.org.uk/co-production/over-a-brew-virtual-coffee-sessions .

The session was powerful and led to some really open reflections from practitioners in particular the assumptions that are made about those who need care and support wanting it to be provided by a family member or not, how much we really involve carers, get to know them, really understand what they need in terms of information and advice. There was some really open and honest discussions in breakout rooms that are reflected in the rest of this document, Take time to watch the videos, and reflect on the feedback and comments included here.

"One of my dreams as a carer is being given something before I actually need it as a carer!"

Poem on being a Carer by Jacqui Darlington

"The day I gave birth to my youngest son Joshua changed how I felt as a mother.
After giving birth I was put into the most dark and dismal small room you could think possible
in the hospital. And it was there with that I was brutally told by a pediatrician oh yes he has got
Downs syndrome as he walked away leaving me stunned. I had no idea or even suspected
that my beautiful son had any disabilities at all. The following day a midwife came in and said
Ive never seen a black Downs baby before which led me to believe that the child I produced
was abnormal. How wrong could I have been? Once home I was visited by my GP who was so
shocked that Id had a child with down syndrome practically ran out of the house. He later
phoned me to apologise and said he had not read the notes before attending. A few weeks
later I met another mum who apparently gave birth the same night as I did to her son who also
has Down's syndrome and she overheard one of the midwives saying, Oh no not another one
tonight. This was my introduction into being a carer rather than a mother."

Themes that emerged during the session

Identity, emotional impacts and expectations on carers

- *I have decided to be my Father's son and 'not' his carer*
- *Worry about caring role. Am I mothering them? But need to keep them safe. Can affect dynamics of relationship*
- *Being out in public - seeing adverts for live in carers and people assuming that 'unpaid carers' are in paid for roles*
- *Stigma, assumptions and misconceptions and good intentions*
- *we reflected on the stress and anxiety of being a carer*
- *Feeling excluded/marginalised when friends/family stop inviting you to occasions and/or inviting the person you are caring for along - loss of identity*
- *Things keeping us up at night - the guilt and worry, as well as the practical things, supporting people to get to the loo etc - and the knock on impact on people the next day in work, life roles etc - makes everything harder.*
- *In our group we reflected on the stress and anxiety of being a carer*
- *Expectation you are always there to care when you are caring for a family member*
- *Expectation and pressure of always being available for the person...*
- *When you are a carer for life it is difficult adjusting when they have passed away*
- *Financial worries and strains if you are no longer able to work full time*
- *The issue of identity and loss of identity*
- *Wanting to be seen as the person not the carer - the mum, wife, partner, daughter - what ever is right for them*

Themes that emerged during the session

Help, support and information needs

- *Identify needs and support that carers require*
- *Wants to feel identified and have help and support , it should be everywhere, the best information is from word of mouth*
- *Keeping us up at night: worries of caring and future. Guilt.*
- *Physical needs and balancing lack of sleep with the demands on the carer of daytime needs in attending meetings, appointments and work.*
- *They're taking a lot of responsibility on them. They need a break*
- *Emotional wellbeing: Guilt. Carers will not always acknowledge their own emotional needs as their priorities are for the person they care for. Admitting needing the help to others.*
- *Burnout: keep going, only calling for help at burnout stage. Physical demands.*
- *Interesting to hear about the lack of cut off - it's not 9-5 - where is the line between just helping someone out and being a carer- and when does it end.*

Themes that emerged during the session

Service design and information

- *Future and contingency planning, what would happen to that person? Would the person be listened to? Would there be an advocate for them?*
- *Having services that are more joined up and not in silos. Information out there.*
- *Why can't carers information be everywhere GP, church, library. Not everyone has access to internet. Making information more readily available. Carers have some priority.*
- *Offer counselling or support groups, can help stress, manage isolation*
- *Counselling support very important*
- *Also provide financial support as well as emotional*
- *Provide respite to carers for recharge and rest, they work a lot of hours*
- *Provide training, first aid, techniques for stress*
- *Support for young carers,educational support, social activities*
- *Opportunities for carers to provide feedback*
- *We would want to have early intervention, and know what support was available to people...*
- *Early intervention from getting GP appt when the issue is small rather than urgent, to provision of service to support development rather than when getting to burnout*
- *The small things that we can find to make things easier - like the OT who can make an adjustment - lets try and find out what is possible and personalised for people that will help people know they are valued, people felt asked and listened to...*

Themes that emerged during the session

Involve and listen to Carers

- *Do social workers ask the cared for? Include them in the decision about if carers are family members*
- *For all professionals to accept that the carers are the experts and not dismiss and to take on board what they are saying.*
- *Get to know the person and know what's best for them- having peace of mind based on what you're able to offer them*

Themes that emerged during the session

Recognise the value of carers

- *What if that person wasn't there caring? Would some then qualify / meet eligibility?*
- *Knowing that you're making a difference in that person's life and wellbeing because the person may not be able to verbalise it. The cared for person is not worried because things are being taken care of, for example, getting medication.*
- *Appreciation for carers*

Themes that emerged during the session

Understand the diversity of Carers

- *Younger carers - perception that it is more older people that are carers - but young people are carers too - touched on the services of charities like Parkinsons, Alzheimers society and the early support*
- *Carers are from all walks of life, there is no one definition*
- *Often misconception about what a carer is out in the public arena - not all paid*

Final reflections

The feedback from the session was a powerful reminder of how important the issue of carers is, and how this is different to people supporting in a paid care worker capacity.

It highlighted again the importance of genuine co-production with people, human connection, deeply listening and proactively involving people in conversations about all aspects of their caring roles. And how the views of carers should be included in all aspects of co-production, not just the bits we assume relate to them.

There was honest reflection on how this learning needs to be explored further through the regional carers network, and an acknowledgement that the learning from the session highlighted issues that people are not fully aware of currently, including the emotional impact on carers - one person commenting 'its bigger than I thought'

Although caring can be incredibly hard - with the right support it can be rewarding...
''Seeing the achieving of the person they support. The adult being comfortable. Seeing the adult being able to develop their own skills. The fun moments that make us giggle.''

Ultimately though what came through loud and clear beyond understanding the emotional impact, was the power of listening and then responding to what carers say, and reflecting that in the ongoing service design, how we provide information and advice, and ensuring that we are responding in ways that truly value carers, and the diverse community of people who are identified as carers.
Finally, as we said in the introduction, please take time to watch the videos and reflect on what comes up for you, and to share these resources as widely as possible to help improve the experiences carers have across the Eastern Region.

Feedback and takeaways from the session

Listen before assuming know what's best

I didn't realise how much the emotional drain impacts on carers - it is bigger than I thought

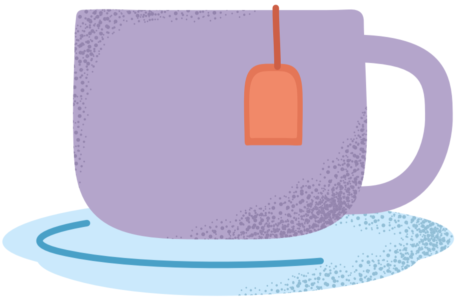
Feeding back the themes to the regional carers network in October so we can work together to find solution and improve

We definitely need to challenge/explore the assumptions as a regional carers network - hearing this

You can never hear too many carer stories or wise words....so powerful

Today highlighted that the voice/perspective of unpaid carers and people who are supported by unpaid carers needs to be represented in service conversations

A really thought provoking session and a helpful reminder



You can spend all day with somebody and still be alone.

We can commission these things privately and it saves money as well as heartache.

Carers Assessment are NOT about assessing the carers ability to care.

Great insights from others great to hear from everyone I was with in breakout rooms and main room

The importance of hearing what people are saying, allowing space and not jumping to conclusions or assuming you have an answer to fix things.

Feedback and takeaways from the session

CURATORS OF CHANGE

Thank you for today's session, it was my first session I found it enlightening and inspiring

Thank you for a great session today - I don't think any of us will understand fully the emotions carers go through, their mental health as well as their own health is affected. I can relate to Hameed's story!

It was a good session to hear some ideas for best practice and sharing this onwards

There are rewards from being a carer - however not going to happen for everybody - lets not assume that being a carer is always rewarding.

One of my dreams as a carer is being given something before I actually need it as a carer!

I am overwhelmed by today's session. Jaccqui's experience was so moving, and Hameed's experience was very honest. What a privilege to listen to other experiences, and also think about the carer as a person and not a title.

It was good to hear from carers to hear how professionals refer to them. The importance of support for carers and for them to keep the role that they have within the family.

Need to join the dots more - lots out there, commissioned, voluntary community but if we are not told, how do we know!

It's important to keep talking to carers about the future contingency planning.

Thank you, thought provoking and inspiring

Didn't hear much about isolation

We need to (as carers) keep on making the case, keeping this on the agenda, and sharing what we already know.

Co-production needs all stakeholders, especially staff delivering services

CURATORS OF CHANGE

Thank You!

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Please join us for the next session on 30 October 2024… to talk about Transitions, Over a Brew!