

HOW DOES IT FEEL FOR ME?



Dee and Gina's story summary report



Context

This work is part of a wider approach being taken in Leeds to understand people's experiences as they move around health and care services, called the 'How does it feel for me?' programme. As well as the real-time journeys that we are following, there are three additional components to the programme: case note reviews, understanding what citywide complaints tell us, and developing a set of metrics (data measures for tracking progress) that will be used to measure joined-up health and care services. The project involves all health and care partners, including representatives from Healthwatch Leeds, Leeds Teaching Hospitals Trust, Leeds Community Healthcare NHS Trust, GP Confederation, Leeds and York Partnership NHS Foundation Trust, Leeds City Council, Carers Leeds, Age UK and St Gemma's Hospice. The project is designed to help partners to understand what people's experiences are like as they move through 'the system'; identify what is working and what is not; and think about how they can plan and deliver services better. Increasingly, as health and care services work more and more in partnership, this work will feed directly into the Integrated Care Partnership for Leeds.

For more information on this project, please visit our website

<https://healthwatchleeds.co.uk/our-work/how-does-it-feel-for-me/> or contact harriet@healthwatchleeds.co.uk

Background

Dee and Gina are a couple living in East Leeds. Dee used to enjoy doing alternative therapies and Gina enjoys crafting. Both have long-term mental and physical health conditions; Gina also has undiagnosed Aspergers. They both care for each other.

Dee and Gina wanted to take part in the project so that services can learn from the people who use them and help other people who might be in a similar position as them.

We followed Dee and Gina's journey between October 2022 and July 2023 in a series of filmed updates.

Themes and key messages

Below we have summarised some of the key themes arising in Dee and Gina's experiences. We start with the '3 Cs' – communication, compassion, and coordination – the essential building blocks for good person-centred care. We have also summarised further themes that came up in Dee and Gina's interactions with health and care services.

Communication and coordination

For Dee and Gina, the themes of communication and coordination are closely interlinked. When communication is good, effective coordination follows. When communication is not good, coordination also falls down.

“I think the one thing I'd change...was services being more linked up, speaking to each other and communicating more, just between themselves as well as with me as well, so that everyone's on the same page and everyone knows when things are happening, and that they haven't sort of just fallen through a gap and been forgotten about, which is what I feel like all the time.” (Gina, October 2022)

Gina talks about the need for better communication and coordination on more than one occasion. In her first update, she describes the gall bladder surgeon, hepatology department and liver specialist not talking to each other and, “definitely not communicating with me, so I'm left sitting wondering where I'm going next.” (Gina, October 2022).

Gina also talks about the difficult and confusing nature of navigating getting an autism assessment after a negative experience with her GP (November 2022 and April 2023).

In April 2023, Dee and Gina gave three examples of miscommunication or poor communication between services and themselves. The first experience they shared was regarding a dental x-ray that was assumed to have been done because it should have routinely taken place at a face-to-face appointment but didn't because Dee's appointment was by phone. This resulted in delays of "three or four months." The second example was poor communication regarding a change of Dee's physio appointment from face-to-face to phone, which she told us never materialised. This resulted in the service automatically sending texts to say that she hadn't attended her appointment, leaving her in the position of wondering if she'd been discharged from the service as a result. The impact on Dee is potentially quite serious in that she implies that she may not try to communicate with the service again which could result in her being discharged and missing out on treatment.

"Yeah, I'm in pain, and yeah I'm going to suffer now because I don't have the energy to fight." (Dee, April 2023)

The third example is the confusion around the type of patient transport that is sent for Dee which when it arrives is deemed unsafe. This results in the driver refusing to take her but not putting in place alternative arrangements, meaning that she misses her appointment.

Gina does share a couple of examples when things were communicated well. Firstly, her experience with neurology:

“I’ve now been discharged from neurology... I felt reassured that the issues that I had... had been confirmed and sort of like sorted out, and that I had a doorway if I needed to go back.” (Gina, January 2023)

And secondly, her experience of the endoscopy when the consultant was present at the appointment and was able to give her the results straight away.

“Having the results direct, as soon as I walked out, it was very useful.” (Gina, January 2023)

Both Dee and Gina’s experiences highlight the confusion that can arise for people who have multiple contacts with healthcare providers and the negative impact in terms of delays, stress and wasted time for healthcare professionals. There is a vital role for professionals to make sure that communication is clear, and that information has been correctly understood.

Compassion

Compassionate care makes both Dee and Gina feel reassured, listened to, and valued as a person. We see several examples of good compassionate care:

When Gina has her endoscopy appointment...

“The ones [staff] that were in there were extremely calming because they knew I was extremely nervous... I was made to feel reassured, cared for and looked after throughout.” (Gina, January 2023)

When she sees the neurologist...

“He listened to me... I definitely felt like he was taking time out to talk to me as a person, gave me the time I needed to explain things.” (Gina, January 2023) Neurologist

Dee also shares how she felt when the surgeon didn't consider the impact that his communication and lack of explanation had on her, and then the kindness shown by the nurse to reassure her:

“...the surgeon that I was talking to said, “Well, you're on a CPAP machine, so probably should warn you that I've had a couple of little problems with people with CPAP machines,” and he left it at that, he didn't explain it, so I got myself a bit upset about that, and stressed out, and then the nurse that was seeing to me yesterday, she said, “Look... I know what you're worrying about. Don't panic.” (Dee, April 2023)

Family carers

“You're my mental sort of carer, I'm your physical carer.” (Gina, October 2022)

Dee and Gina's mutually supportive and caring relationship is very important to them. They care for each other but feel that this is not always recognised, partly because Gina's disability isn't so visible, but also because she has no formal Autism diagnosis.

“We've both got disabilities. Mine you can see. Gina's you can't... until she actually falls apart.” (Dee, November 2022)

Gina feels that she is not taken seriously at PIP (Personal Independence Payment) assessments; Dee cannot get Carers Allowance, and she is confused about whether she can access support from Carers Leeds because she thinks she is not “legally” a carer. It also means that she feels ill-equipped to care for Gina.

“...because I don’t know what level she’s at, I don’t know what I should be doing to help her.” (Dee, November 2022)

Dee also comments that she feels that because they’re seen as caring for each other, they are not offered the full range of external support.

“If you’re living on your own, we can come and help you. Because you’re a couple, deal with it.” (Dee, October 2022)

Dee talks about the emotional impact that caring can have on Gina and the importance of them having a break from each other and Gina mentions a positive experience of accessing support groups and activities at Carers Leeds.

“I'm sort of a bit mindful as well that she's got a bit of time away from me because 24 hours a day, seven days a week could be too much for anyone, given what I can be like, and I do get upset.” (Dee, November 2022)

They also describe how caring for and being cared for by each other can be a juggling act, when Gina has to book in for her endoscopy and they have to consider both of their needs (November 2022).

Digital and phone access

A common theme in the videos is the choice and appropriateness of telephone appointments. Sometimes choice is offered for the type of appointment, such as for Dee's physio appointment in January 2023, and sometimes it isn't, e.g., when Dee has a rheumatology appointment in October 2022. Dee finds this very frustrating.

“...talking down a telephone... you can't see what my bones are like, and what my bones are doing.” (Dee, October 2022)

Dee also describes having a physio appointment over the phone and being sent a link to an exercise app which concerned both her and Gina in that without proper instruction she may be doing more harm than good.

“No demonstration of the exercises. No way of seeing that she’s actually doing them, and not hurting herself further.” (Gina, October 2022)

Gina describes a positive experience of a hepatology appointment she has by telephone:

“It wasn't a rushed call, she made sure that everything was explained very clearly to me, what was going to happen, how it was going to happen, and they had the plan in process... it's just left me with a little bit more confidence that things will be okay and sorted.” (Gina, July 2023)

Their experiences highlight the need for people to be given informed choice and all the information they need for an appointment to be effective.

Gina describes how the move to email communications isn't always good for her in that it has resulted in her missing out on seeing activities that were going on at Carers Leeds.

“They [Carers Leeds] used to send a paper newsletter out which was really handy, because if they send me an email it gets lost. I don’t always check my emails, so if I don’t know it’s coming out, I don’t look for it.”
(Gina, November 2022)

Conversely, Gina surprises herself that booking an appointment online was actually “quite easy”, although she does again talk about how having a physical paper confirmation makes things easier for her to remember.

“I like to get it like that as a link in my phone and open it up, but once I’d confirmed the appointment, I would have preferred if they’d have sent a letter afterwards, so that I’ve got a paper form to remind me, because I do tend to sort of forget to look at my phone.” (Gina, January 2023)

Involvement of the person receiving care and their carer

“With physio, I felt as if they actually listened to what I said and took everything into account this time, instead of just wanting me to do exercises, they listened to me saying, “Look, I really am struggling.””
(Dee, January 2023)

Dee's experience above was really positive because she felt listened to and that her own unique situation was taken into account. As well as being involved in their own care, for both Dee and Gina, being involved as carers in each other's care is also important. In October 2022, Gina recalls Dee being in hospital and feeling like they were talking to everyone except her, despite her being the one who knows Dee best.

"It's really important that carers are listened to as well as the patient, because the carers see the patient day in, day out. They know that person's baseline, they know what's their normal." (Gina, January 2023)

Gina values being given the option of having Dee with her at her neurology appointment (January 2022). She also highlights the emotional reassurance that comes from being able to have her partner and carer with her and comments on whether this could be extended to the pre-operation/sedation stage.

"If there's one thing I would have to add to make the experience a lot easier to cope with, then I would choose that my partner can be with me 'til they put me under sedation [for endoscopy]." (Gina, January 2023)

Waiting lists/Impact of Covid

Dee describes how Gina has been waiting two years for her liver and gallbladder surgery because of the “backlog from Covid” which is causing Gina lots of health problems She also describes how she will be waiting “three years” for an Autism assessment because of difficulties navigating the system along with current waiting lists. (November 2022)

How this report should be used

The insights from this report should be used by health and care organisations in Leeds as part of their ongoing Quality Improvement work. The insights should also be used by relevant Population Boards to inform discussions and decisions. In addition, the reports will feed directly into the Leeds Health and Care Partnership, including the citywide Person-Centred Care Board and the Quality and People's Experiences Committee.

If you use this report to prompt any improvements in your organisation or the wider health and care system, please let us know by contacting harriet@healthwatchleeds.co.uk. This enables us to track impact as well as feeding back to participants the differences they are helping to make.

Questions for Leeds Health and Care Partnership:

The Leeds Health and Care Partnership is made up of health and care organisations that work together and use their resources collectively to improve people's health and reduce inequalities by delivering joined-up person-centred care. We would like the Leeds Health and Care Partnership to consider the following questions:

1. At a system level, what needs to happen differently for all our services to co-ordinate well?

2. What do Dee and Gina's experiences tell us about the importance of having a culture of compassionate care, and how can we ensure that this is consistent across the system?
3. What do we need to do as a system to improve communication so that people like Dee and Gina will always have a good quality experience and good outcomes?
4. How might Dee and Gina's experiences have been different if services had been operating to the principles of an integrated care model – i.e., co-designed, jointly commissioned and delivered in partnership to achieve shared outcomes?

Questions for individual organisations and Population Boards:

We would like health and care services to use this report and Dee and Gina's videos within their teams as a learning and development tool.

Below are a series of questions that could be used as conversation starters in conjunction with this report alongside the video updates:

1. What would your services need to do differently to make sure Dee and Gina always felt like they were treated with humanity, warmth and empathy?

2. What would your services need to change to ensure that Dee and Gina both as individuals and carers were always involved as an equal partner in plans and decisions about their care, and make use of any skills and knowledge they bring?
3. What more could your services do to recognise and support the vital role of family carers, for both visible and 'invisible' health conditions?
4. How will you check that people like Dee and Gina are always given clear information and advice at every stage in a way they can understand?
5. How can you ensure that people like Dee and Gina are always given the choice where possible of how they want to access services, i.e., face-to-face, phone or digital?
6. What opportunities exist for staff to work across organisational boundaries so that they acquire new skills, adopt ways of working and communicate better with each other?
7. Within your service what's the smallest change that could make the biggest difference to people like Dee and Gina?

Appendix 1: Actions from Partners

Organisation	What actions have you taken, or will you take as a result? And where will you share the videos or updates?
Leeds Integrated Care Board	<p>January 2023 - could be used at a Primary Care Target event when looking at personalised care and shared decision-making.</p> <p>April 2023 - can be used at primary care collaborative care and support planning training to enable people to feel difficult patient experiences.</p>
Age UK Leeds	<p>Videos will be shared with staff as part of a programme of practice reflection that has been initiated.</p>
St Gemma's Hospice	<p>Share through the Involve group that brings together all the hospice's patient and public involvement work with staff inclusion work.</p>
Leeds Community Healthcare NHS Trust	<p>Videos will be shared with:</p> <ul style="list-style-type: none"> • Clinical/Quality Leads to be shared within services/ teams.

	<ul style="list-style-type: none"> • The LCH services referred to within them directly with an ask to review and consider where improvements can be made/feedback to share. • Trust Boards meetings where appropriate as part of the Patient Story agenda item. • They will also consider how else the videos can be used across the organisation as part of current Engagement principle development work. • Learning will be highlighted in newsletter/reporting structures. <p>Specific feedback and videos to be shared as follows:</p> <ul style="list-style-type: none"> • January 2023 – neurology and musculoskeletal services. • April 2023 – musculoskeletal and community dental and Wharfedale Hospital services.
Carers Leeds	<ul style="list-style-type: none"> • November 2022 – feedback to the Carers Leeds team about experience of Carers Leeds and look at ways we can improve our communications. Further promote the work that is happening in Leeds on contingency planning for carers.

	<ul style="list-style-type: none"> • January and April 2023 – shared with the Carers Leeds team.
Leeds Teaching Hospitals NHS Trust	<p>Videos have been shared at the Trust Patient Experience Group. They have also been shared with the following:</p> <ul style="list-style-type: none"> • Introduction – shared with Carer’s Group as Dee and Gina demonstrate that carers come in all sorts of configurations and that both participants function as a carer for the other. • October 2022 – shared with Abdominal Medicine and Surgery Clinical Service unit (CSU) regarding Hepatobiliary team; with Chapel Allerton Hospital and Adult Therapies CSUs regarding telephone appointments; and with Carers Group regarding not feeling listened to in the role of carer. This video will also be included in the carers training that the Trust provides to staff. • January 2023 – shared with Abdominal Medicine and Surgery (Endoscopy), Adult therapies and Neurosciences. Feedback regarding appointment booking and suggestion of confirmation letter shared with Patient Hub Team. Commitment to exploring why carers are unable to be with person

	<p>during pre-operation/sedation and looking at if that can happen.</p> <ul style="list-style-type: none"> • April 2023 – shared with Leeds Dental Institute and Adult therapies for learning. • July 2023 – shared with Abdominal Medicine and Surgery Clinical Service Unit regarding positive experience with Hepatology. • July 2023 – The general point about including carers in conversations is one that we will be promoting when we do an awareness raising / refresh of ‘John’s Campaign, later in the year.
<p>Leeds City Council Adults and Health</p>	<p>October 2022 – Discussed with staff regarding Dee and Gina being treated incorrectly in terms of not being assessed for support because they are caring for each other.</p>
<p>Other places the videos have been shared and action taken.</p>	<p>Videos have been shown and discussed at the following boards:</p> <ul style="list-style-type: none"> • Long-term conditions population board who are organising a multi-disciplinary team to look at the link between long term conditions and mental health, including the needs of carers.

Appendix 2: Index of Dee and Gina's updates

All updates are available at <https://healthwatchleeds.co.uk/how-does-it-feel-for-me-dee-and-gina/>

Update title and link	Summary of content
Intro https://youtu.be/ypu8RIHxLe4	<ul style="list-style-type: none"> • Dee used to enjoy doing alternative therapies. Gina likes crafting. • Both describe themselves as friendly. Dee likes to help other people, and Dee isn't fazed by a challenge. • Both have fibromyalgia and various other long-term conditions (mental and physical health). Gina has Aspergers. • Wanted to take part in the project to help others and so that services can learn from people who use them.
October 2022 update	<ul style="list-style-type: none"> • Gina – gall bladder surgeon, hepatology and liver specialist – poor communication with each other and her. • Dee – Rheumatology appointment. Lack of confidence in thoroughness of telephone

Update title and link	Summary of content
https://youtu.be/SiaDF765LqM	<p>consultations or appropriateness of doing physio via an app.</p> <ul style="list-style-type: none"> • Role as carers for each other – lack of formal diagnosis for autism means that Dee doesn't know how to support Gina properly. Feels there is no support from outside because they're seen as a couple who support each other. • Gina – doesn't feel listened to as Dee's carer at the hospital, despite her feeling that she is the one who knows Dee's condition best. • Dee – enjoying couples counselling – feels seen. • Dee – would like the Council to understand that they've both got disabilities despite some of them being not so visible. • Gina – would like services to be more joined up.
<p>November 2022 - https://healthwatchleeds.co.uk/wp-content/uplo</p>	<ul style="list-style-type: none"> • Experience of Carers Leeds and ongoing support / confusion from Dee about whether she can access Carers Leeds if she doesn't get Carers Allowance. • Experience of LTHT PALs/Healthwatch • Issues around caring for each other when one of them has an endoscopy requiring sedation.

Update title and link	Summary of content
ads/2023/05/Dee-and-Gina-Nov-2022.pdf	<ul style="list-style-type: none"> • Cost of taxis to appointment if not eligible for patient transport. • Gina’s experience of trying to get ASD assessment/referral from GP via a telephone appointment and difficulties with this.
<p>January 2023</p> <p>https://youtu.be/Kcn6eCiOt-M</p>	<ul style="list-style-type: none"> • Gina – endoscopy appointment – good experience with consultant – felt reassured and cared for. Received results straight away. Would have liked carer to remain with her during pre-operation sedation. • Dee – rheumatology physio appointment – good experience, felt ‘taken into account’. Choice of face to face or telephone appointment. • Gina – neurology appointment – positive experience of booking online. Felt listened to, given time to explain things, good follow up. Dee as carer allowed to accompany her. • Importance of carers in knowing the patient’s ‘normal’ and picking up when things are not right.

Update title and link	Summary of content
<p>April 2023</p> <p>https://youtu.be/Gwfc_ZOgBu4</p>	<ul style="list-style-type: none"> • Confusion/miscommunication about whether Dee's dental x-ray appointment at Wharfedale is by telephone or in person. • Dee's appointment for a dental procedure is at the dental hospital next week. Communication from the surgeon caused anxiety. The nurse reassured Dee. • Miscommunication regarding cancelled Musculoskeletal (MSK) physiotherapy appointment resulted in Dee possibly being discharged from the service. • Gina – biggest concern is how to get an Autism assessment. Previously tried unsuccessfully through GP, now wants to try via Adult Social Care worker. • Dee –Patient Transport Service – inflexibility and confusion resulted in Dee missing her appointment. • Gina – wants services to explain things clearer, talk to each other and keep her and Dee in the loop.

Update title and link	Summary of content
<p>July 2023</p> <p>https://youtu.be/t_IKO6K9xKQ</p>	<ul style="list-style-type: none"> • Experience of trying to get dental treatment when Dee has been deregistered from NHS dentist. Trying to get referred to Community Dental Service. • Gina – hepatology appointment. Good communication, took time, explained things clearly, who to contact. Made her feel confident and reassured. • Experience as carers – difficult being a disabled carer as can't get to hospital for Gina's appointments. • Gina – good experience feeling involved as carer with GP and dentist. Hospital – feels communication isn't as good.
<p>Dee and Gina evaluation</p> <p>https://youtu.be/o4-zhvy6OSE</p>	<ul style="list-style-type: none"> • Dee and Gina share their thoughts on what has gone well being part of the HDIFFM project and their ideas for how it could be made better.