

HOW DOES IT FEEL FOR me?



Emma and Adam'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 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. It is designed to support them to understand what people's experiences are like as they move through 'the system'; identify what is working and what is not; and to 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 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

Emma and Adam are a young couple who live in Wetherby. Emma describes herself as "arty and smiley". She plays the trumpet,

saxophone and flute, loves animals, and enjoys playing Pokémon. She is autistic and has mental health conditions, her most recent diagnosis being recurring depression with episodes of psychosis. Adam is Emma's main carer and support. They wanted to take part in the project to get their voices heard as they have not really felt heard in the past either as patient or carer.

We followed Emma and Adam's journey between June 2021 and June 2022 in a series of filmed Zoom updates.

Themes and key messages

Below we have summarised some of the key themes arising in Emma and Adam's journey. We start with the '3 Cs'- communication, compassion, and co-ordination - essential building blocks for good person-centred care, but also cover some other themes that come up in Emma and Adam's experiences.

Communication

A recurring theme for Emma is the importance for her to have good information prior to an appointment so that she understands what will be happening and can prepare for it. On a number of occasions, this doesn't happen and can leave her feeling confused. It highlights the need to ensure that people understand the purpose of any meetings and appointments so that they have the best possible opportunity to prepare and participate.

“We didn’t really know why we were being called in other than to review. But, in the meeting, like discharge came up, lots of things came up but I wasn’t told this... So, that was confusing for me and hard to understand.” (August 2021, part 1)

Conversely, she shares a positive experience of good practice in enabling shared decision-making. Following a neurology appointment, she is given all the information discussed in her appointment in written format and this gives her time to digest her treatment options and discuss with others involved in her care before making a decision.

“He’s writing us a letter so that I do not have to decide in the appointment so that I could then see all his options in a letter and then talk with Adam and my GP. So, I appreciated that, that was good.” (August 2021, part 1)

Emma also reminds us of the importance of first contact and the basics of introducing yourself and where you are calling from at the beginning of a phone call.

“When they first rang..., I thought it was like a telesales person. They didn’t say what service they were with and just said, “Is that Emma?” And then said, “We’d like to ask you some questions.” And I nearly put the phone down going like, “Sorry, I don’t want to do this” ...so that was really confusing.”(January 2022, part 2)

Emma’s comments about a letter sent by her neurologist are a reminder that people can access their notes and any correspondence about them, and they should therefore be seen as an extension of their

care. Consideration of the language used and how it will be received is so important.

“I got a copy of the letter he sent to the GP afterwards and he said, “Thank you for sending me this wonderful woman”. It was really nice, because in the past I’ve had letters where I’ve had the copy of it, and it says, “Thank you for sending this unfortunate woman,” and it’s felt really bad!” (January 2022, part 1)

This issue of language used in Emma’s notes and the negative legacy it can have is also raised by Adam:

“Whatever is written by a professional in your notes is gospel, regardless of what the patient says, you can’t challenge it. If Emma is written as being manipulative seventeen years ago, that’s what people see when they look at her notes and that’s what everyone goes by.” (June 2021, part 1)

Emma’s experiences capture the inconsistencies in how appointments are communicated to people. In one update, she shares two very contrasting experiences of appointment communications, one very positive and one not so. Her experience highlights the importance of regular communication about appointments, providing reassurance and maintaining trust and confidence.

“And they’ve [Pinderfields] been sending me e-letters to keep me updated on everything, which has been really good. Like, it lets me remember that there is still an appointment, because sometimes I forget. But, on the other hand, when I’ve been waiting for my gallbladder one [Harrogate], I got the notification that I’ll be added to

the list, and then I've not heard anything for months and months. So, I think it would be really good, especially within email era and like the NHS app as well... for people just to say, "Well now you're number 72 on the list"... even if it's still a year and a half until your appointment, at least you know you're still on their radar and it keeps that hope going." (August 2021, part 2)

Feeling heard is a very important aspect of communication for both Emma and Adam. This is demonstrated from a meeting they had with Emma's psychologist in August 2021.

"I think she really took onboard our concerns about like discharge, as well, because I think they're trying to avoid that anyway and making sure that Emma's in control of that element." (Adam)

When Emma doesn't feel heard, it is very difficult for her. She talks about a time when she was in crisis and recounts that her therapist kept telling her, "You're stronger than the voice.":

"I find it hard enough to explain to people why I have to follow something that's only in my head and I know it can't physically hurt me anywhere else. It's very hard. How are you meant to reach out to someone for help and services for saying that you're struggling, and you can't cope with the voice, when their only response is "be stronger than the voice?" (November 2021)

Adam also stresses how important it is, not only to be heard but also for timely action to be taken.

"I think if we could change one thing, I think it's about hearing what we say but then acting on it and not getting wrapped up in the

bureaucracy of the criteria and all that sort of stuff because that delay can have a profound impact on someone's health and well-being.”
(November 2021)

Compassion

Throughout Emma's and Adam's time documenting their journey with us, we see a definite shift in how they feel treated. There is a sense in the later recordings that Emma feels much more seen and cared for than in some of her previous experiences. When asked what one thing she has really valued about her care in May 2022, she says:

“The realisation that a lot of the professionals involved seem really, truly invested in me and my recovery, and me being happy and well, and being the best version of me that I can be. And it's just that realisation that professionals do seem to really care at the moment, and I've not always felt like that is the case.” (May 2022)

In November 2021, during a period when Emma was in crisis and without a care co-ordinator, they describe desperately trying to get Emma some help. At that time the only person they could get to talk to from the Community Mental Health Team was Emma's therapist who they reached out to for help. The initial response from them was not helpful.

Adam: “Yeah, and then almost like something out of a sitcom, the therapist basically got up and said, “Alright, time is up”. And then she almost very abruptly got up and walked to the door to show us out basically, almost like she was angry with us.”

Emma: “That upset me as well because I didn’t understand. I thought she was annoyed.” (November 2021)

One of the key factors that Emma attributes to more compassionate care is staff gaining a better understanding around Borderline Personality Disorder and the associated stigma often experienced by people who are given that label.

“I know that in Harrogate they’ve been overhauling the entire service and giving their new training, especially for people who’ve been diagnosed as BPD [Borderline Personality Disorder] in the past or currently, who may have had maltreatment because of that. They’re really trying to address it and I can see the changes; I can definitely see the things they’re trying to action.” (June 2022)

A year prior to this, Emma had painted a very different picture of her experiences.

“People in services don’t seem to like people with BPD. They think you’re manipulative and stuff so really you get treated really nastily in services for it, and when you don’t even have it and you’re being treated that way and that makes your autism worse. BPD is sometimes used by professionals as a reason not to treat you in that acute situation because they see it as an ongoing thing that they can’t really help with.... It is really difficult. You don’t really ever feel safe. You don’t feel like services are really there for you when you need their help.” (June 2021)

The impact of such stigma and resulting lack of treatment feels very personal for Emma with her describing not feeling “liked” or that she’s “not a nice person” (June 2022).

Co-ordination

Emma and Adam live in Wetherby on the border of Leeds and Harrogate areas and her care is provided by two different Integrated Care System (ICS) areas. The majority of Emma’s mental health services are delivered by Tees, Esk and Wear Valley NHS Foundation Trust, whilst other support and services she accesses are in Leeds. This results in challenges around co-ordination and shared information between services that affect Emma and Adam’s experience of care.

“When you’re split across two areas, sometimes Leeds is usually for the physical health but sometimes also Harrogate. And Harrogate is for the mental health but then sometimes also Leeds. But they never talk to each other... So, nobody really knows where I’m at.” (June 2021, part 3)

Adam gives an example of Emma having a front-facing copy of her crisis plan, how best to support her as an Autistic person on her mental health notes from Harrogate but that these will not be able to be seen if she presents to a Leeds service. We hear about when she attends a perinatal appointment in Leeds, and they don’t have access to her mental health notes. Not only does this waste both Emma and the clinician’s time having to recount her whole mental health history, but also Adam expresses concern over whether important information will be missed if and when Emma becomes pregnant.

“So, it’s about that they don’t have access to Emma’s records, and it’s about how do you make sure the care is joined up, so if Emma was struggling if she was pregnant... the care is joined up and she gets the help that she needs, and it’s not detached I suppose.” (January 2022, part 2)

They also describe how things are duplicated sometimes and that this is a waste of resources.

“So, then people then duplicate something as well as in like: “oh, we should get you sorted with employment support” and I’m like “oh, I’m already with it”” (June 2021, part 3)

Because Emma is Autistic and has mental health problems, it is important for her that there is good co-ordination between mental health and Autism services. She describes a holistic and joined up approach from her mental health services and the positive impact this has had on her mental health.

“Now that mental health services in my area are including the autism support, [my mental health] has gotten so much better.” (June 2021, part 1)

However, in the same update, she also says that mental health and other autism services such as employment services “don’t talk to each other” (June 2021, part 3).

When there isn’t confidence that services are talking to each other, this adds an extra stress on Emma and Adam to co-ordinate and explain their own care to professionals.

“We have to hold all the information ourselves.” (June 2021, part 3)

Emma's experiences highlight the importance of good care co-ordination. We see how difficult things got when Emma was without a care co-ordinator for a period of time, that coincided with a deterioration in her mental health.

“I was deteriorating mental health-wise and my care coordinator was worried before she left and tried to put stuff in place but none of this materialised. So, this last month has been trying to navigate finding a way to get some more help but not succeeding at kind of any point really.”(November 2021)

When she has a good care co-ordinator, it transforms her experience and the impact on her wellbeing is tangible.

“This is probably the best ever that it's been joined up, especially between Leeds and Harrogate and between different services and I think a lot of this is to do with my care coordinator, she's very very good. I think it's contributed to how more positive I feel at the moment as well.” (Emma -May 2022)

It also results on there being less pressure on Adam:

“That is reassuring for me because then I don't have to worry, I don't have to chase up, I'm not left asking questions that puts her on edge... I can just go on with the caring stuff, you know, or the kind of the day-to-day stuff rather than having to try and coordinate that extra stuff as well or figure out what's going on with it.” (Adam -May 2022)

Adam describes how good co-ordination has had a massive impact on Emma feeling supported and ready for discharge.

“She says she’s excited about discharge which is something you’d never think she’d say... and that is because it’s been done right rather than it being a scary thing.” (May 2022)

The pre-discharge meeting has elements of really proactive joined up care, with Emma’s family, her GP, therapist, care co-ordinator and a manager from autism services all attending. Professionals worked together to put things in place that will work for Emma if her mental health deteriorates, such as being able to up her medication dose via her GP rather than wait four weeks to see a psychiatrist.

“It gives you that reassurance and that base of stability that you can rely on that, and that actually helps you stay well.” (June 2022)

The point at which it “falls down” is that the crisis team don't attend the meeting or send any input and Adam acknowledges a lack of trust or good relationship with them. Despite this, there is a promise from the care co-ordinator to chase this up to get a plan in place.

Interplay of physical and mental health and neurodivergence

Emma has lots of issues which are not immediately apparent to others. She has physical and mental health needs that directly affect each other - migraines compounded by stress, and physical injuries resulting from an incident related to her mental health. Layered over this is the fact that Emma is Autistic which is yet another factor that affects both physical and mental health.

“Living with Autism in what they call a ‘neurotypical world’ and mental illness, I end up being stressed quite a lot so they kind of interlink.” (Intro, June 2021)

The combination of Autism and mental health problems means it can be harder for Emma to get the right services, particularly in more rural setting and highlight some of the health inequalities experienced by those who are not neurotypical.

Family carers

“A lot of people who are people’s partners or parents are carers and they just don’t realise it.” (June 2021, part 1)

This can be particularly the case for family carers of people with mental illness like Adam, where the role and impact of looking after someone with mental health problems is often not understood. He describes one weekend when she was in crisis “doing 24 hour observations on her” because the crisis team have not given any help (June 2021, part 2). An important part of Adam’s caring role is to be an advocate to help Emma get her voice heard and get the care she needs.

“I didn’t have a voice, like, kind of before I met Adam, I didn’t really have my own voice to... fight for my mental health and physical health.” (Intro, June 2021)

This is never more evident than in the November 2021 update where Emma describes being mute. In this situation Adam is vital in communicating what is going on for Emma and pushing to get the help she needs.

When we first meet Adam, he describes feeling “rarely listened to” (June 2021, part 1). Emma describes an experience during an appointment with her psychologist where she feels her wish for Adam to be present as her carer and advocate aren’t considered.

And she kept asking “can we get Adam to leave?” She didn’t want you in that appointment. She kept saying “can I just speak to you on your own”. And I was like, “No, I want Adam to be here because he can speak for me, and he can also help me reality check after the appointment.” (November 2021)

Some months later, we see positive examples of where he is involved as a key partner in Emma’s care such as in the perinatal appointment (January 22, part 2) and pre-discharge meeting (June 2022).

“She mostly wanted to speak to me but then she thought it’d be good to have Adam in as well, so it felt like she cared about listening to both of us.” (January 22, part 2)

Similarly, Adam goes from a time where he says that he’s never been offered support as a carer (June 2021, part 1) to getting referred Carers Leeds in January 2022 and by May 2022 starting to access their support. His experience of Carers Leeds is positive, but he does highlight the need for increased options for carers who work 9-5 such as more virtual and evening/weekend support.

In August 2021, Emma and Adam describe an experience where having an unpaid carer becomes a barrier to accessing support. They report being advised (incorrectly) that having Adam as her carer, can affect the outcome of Emma’s assessment for autism support (August

2021, part 1). This is a theme that we have heard before reported by people with family carers.

Geographical Access

Navigating and finding the right services to access can be a challenge for Emma and Adam mainly due to where they live. Living in Wetherby makes it more difficult to access Mental Health and Autism Services because it may be paid for by one area but delivered by a provider in another area. Sometimes services are recommended by care coordinators but are too far away and become a barrier to access.

“Even if I do find something to access in Leeds that I have been told that I can come to cause we finally found someone who will accept me, I sometimes can’t get to it or give up on continuing to access it cause it’s so hard to get to by myself.” (June 2021, part 3)

Sometimes they are not eligible for some services despite accessing other services in the same area. Adam recalls seeing a poster for carer support in a Harrogate hospital that Emma was in but being told, “Oh, well you’re not from this area so you can’t access it.” (June 2021, part 1). And then again when they talk to Emma’s care co-ordinator about possible carer support, they don’t seem to be clear about whether Adam should access this in Leeds or Harrogate resulting in a long delay (January 2022, part 1).

Digital and phone access

On the whole, Emma has had positive experiences of accessing appointments by phone or video call and can also see the advantages of it in terms of accessing appointments sooner. She describes accessing her GP:

“I’ve actually found it really beneficial to be able to have a telephone call so much more readily because it meant I was able to get an appointment each time on the day of ringing rather than waiting like two weeks or three weeks... And the times where over the phone they’ve realized, ‘Oh you need to come in’, I’ve been asked to go in... so I think it’s been working really well.” (January 2021, part 1)

It also removes the transport barrier, which living out in Wetherby is often a problem.

“I actually preferred that it moved to Zoom if it was going to be in Armley, the perinatal appointment, because that would have been a difficult place for me to get to... because I wouldn’t have been able to do it on public transport myself.” (January 2022, part 2)

In terms of improving access, one of Emma’s recommendations is for services to routinely be more proactive in offering appointments in different formats (Zoom, phone or face to face) when appropriate, to give people more choice (January 2022, part 2).

Involvement of the person receiving care – understanding their needs and wishes

Emma and Adam are both clear that a good mental health service would be more effective in preventing crisis if they were more person centred, considered what the person needs and are clearer on agreed outcomes between the professional and person using the service (June 2021, part 2).

There are examples of this in their experiences, for example when they meet with the Community Mental Health Team to have proactive conversations about discharge which involve both Emma and Adam.

“They wanted to have a meeting with us this morning to see if we were all on the right track. I think that’s good: wanting both my opinion and Adam’s opinion as my partner.” (August 2021, part 1)

How this report should be used

The insights from this report should be used by all health and care organisations in Leeds as they start to reset their health and care services post-Covid and as part of their ongoing quality improvement and learning work. In addition, the reports will feed directly into the new governance for the Leeds Health and Care Partnership, including the citywide Person-Centred Care Expert Advisory Board and the Quality and People's Experiences Committee.

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 Emma and Adam'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 Emma will always have a good quality experience and good outcomes?
4. How might Emma and Adam'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:

We would like health and care services to use this report and Emma and Adam'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 and Emma and Adam's videos:

1. What would your services need to do differently to make sure Emma always felt like she was treated with humanity, warmth and empathy?
2. How can you work with other services to ensure better co-ordination of care and access for people like Emma who live on a rural geographical boundary?
3. What would your services need to change to ensure that Emma was always involved as an equal partner in plans and decisions about her care, and make use of any skills and knowledge she brings?
4. How will you check that people like Emma and Adam are always given clear information and advice at every stage in a way they can understand?
5. How can you ensure that people like Emma and Adam are always given the choice where possible of how they want to access services, i.e. face to face, phone or digital?
6. How will you consider the emotional and mental health impact of having long-term health conditions and/or being neurodiverse on

both the individual and their family carers when designing, monitoring and improving services?

7. 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?
8. Within your service what's the smallest change that could make the biggest difference to people like Emma and Adam?

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? |
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| Leeds and York NHS Partnership Foundation Trust | <p>Emma and Adam's videos have been used to open their 'Unified Clinical Governance Meetings' (which are attended by Clinical Leads and Heads of Services), to set the scene and remind staff members that people using services and carers should be central to all that they do.</p> <p>They have also played Emma and Adam's videos at the following meetings:</p> <ul style="list-style-type: none"> • Experience, Involvement and Carer subgroups • Triangle of Care Champion Meetings. These are meetings designed to improve the involvement of Carers throughout services including staff awareness, carer support and suitable carer policies. • Preceptorship meetings for Occupational Therapy, Nursing, Health Care professionals. Preceptorship meetings are held with newly qualified staff members as they transition from student to practitioner. • Crisis team clinical governance meeting (to show how important it is that they are involved in discharge planning meetings.) <p>Some of the actions they have committed to are:</p> <ul style="list-style-type: none"> • Remind staff of the importance of listening to the carer – they know how the person is when they are well/unwell. (June 2021) • Offer a choice where possible in how people would like their support to be provided (ie. phone/video call/face to face etc) (Jan 2022) |

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| | <ul style="list-style-type: none"> • Remind staff to make people aware of the support that can be accessed from Carers Leeds. (Jan 2022) • Be clear in letters/phone calls what people can expect to happen at appointments. • Remind staff that they should always introduce themselves at the beginning of a conversation (phone or in person) with a person accessing a service with their name, role and service. • Check with the Autism service that people are not disadvantaged by having support from a carer. (Aug 2021) |
| Leeds Clinical Commissioning Group (CCG) | <p>They have shared the June 2021 videos in the following places:</p> <ul style="list-style-type: none"> • Leeds Mental Wellbeing contract review meeting • Complex needs Business unit (to cascade to any services they work with in respect of mental health and autism) • LYPFT Quality Engagement Partnership Group <p>Some of the actions they have committed to (June 2021) are:</p> <ul style="list-style-type: none"> • Raise awareness about the inequity of service and access which may be felt by patients living on the borders of different geographic areas. • Try to encourage more joint working and better communication across different geographical areas. • Raise awareness about people who may be labelled with Borderline Personality Disorder or anything else which may affect how they are treated within mental health services. • Raise awareness of family carers and the fact they may need more support and recognition. • Try to influence (where possible) change in the way mental health services operate by |

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| | <p>encouraging a more patient focused approach and more focus on preventative mental health support rather than reactive.</p> |
| <p>Leeds Community Healthcare NHS Trust</p> | <p>They will share videos with services to raise awareness of issues with:</p> <ul style="list-style-type: none"> • Appropriate clinical/Quality Leads within Business Units (eg. Leeds Mental Wellbeing Service). • Engagement champions across the Trust. |
| <p>Carers Leeds</p> | <p>Videos have been shared with Carers Leeds staff team as a learning and reflection tool and on Carers Leeds social media channels. They are also planning to use them in external sessions in the future to raise awareness with primary care and community services professionals.</p> <p>They have also committed to the following actions:</p> <ul style="list-style-type: none"> • Use June 2021 video to act as a prompt to think about what more Carers Leeds can do to support carers to act as advocates in partnership with the people they care for. • Promote their work more with Mental Health Care Co-ordinators so that carers become aware of their services earlier. • May 2022 video was used as part of Carers Leeds review of their group work offer including how and when groups are offered to enable participation by working carers. It also prompted them to promote their evening groups more widely. • Aug 2021 – follow up with adult social care about assumptions that people don't need assessments/additional help if they have an unpaid carer. This should not be the case. |
| <p>Leeds Teaching Hospitals NHS Trust</p> | <p>Videos have been shared at the Trust Patient Experience Group. They have also been shared with the following:</p> |

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| | <ul style="list-style-type: none"> • June 2021 (part 1) – Equality and Diversity (patients) and Carers working group membership. • August 21 (part 1) – Neurosciences and Radiology clinical support units. • August 2021 (part 2) – Outpatients and Acute Medical Services clinical support units. • January 2022 (part 1) – Neurosciences clinical support unit and outpatients Referrals and Booking Service regarding that letter didn't state full purpose of the appointment meaning person wasn't prepared for treatment. • January 2022 (part 2) – maternity team |
| Age UK Leeds | <p>Videos have been shared with service managers and teams within the organisation.</p> <ul style="list-style-type: none"> • August 2021 (part 2) – shared with teams which currently operate a waiting list and ask them to reflect on it and what they could do differently within their service in terms of communication with people. • Raise the issue of those supported in boundary areas and check what challenges the different teams are aware of and whether we could do more to support. |
| St Gemma's Hospice | <p>Videos are shared with staff teams and Involve (the group in the Hospice that draws together all their patient and public inclusion work) – to highlight good practice and when things could be better in terms of person-centred care.</p> <ul style="list-style-type: none"> • June 2021 (part 3) – will ask the community teams how people living on the borders of geographical areas impacts on their care. • Jan 2022 (part 1) – Check if community staff follow up with a message if a call is not answered. |

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| <p>Leeds City Council Adults and Health</p> | <p>Videos have been shared with the following:</p> <ul style="list-style-type: none"> • Adults and Health commissioning managers meetings • Carers commissioners • Operational social Care staff team meetings. • Complaints team. • Regular team meetings across Adults and Health. <p>The following comments/actions were also highlighted:</p> <ul style="list-style-type: none"> • August 2021 (part 1) – having a carer should not be a barrier for people to receive support – discuss with operational staff about how important it is to support carers. • August 2021 (part 1) – there is currently a review of ways to access Adults and Health services. This will look at the way information is presented, taking accessible information into account. Digital innovation is also being considered and the best way to support people using the latest technology. Processes will be more streamlined and hopefully less confusing for people and professionals alike. • Raise the carer profile and importance in supporting not only the person but also the services and processes. |
| <p>Other places the videos have been shared and action taken.</p> | <p>Videos have been shown and discussed at the following citywide and regional leadership groups:</p> <ul style="list-style-type: none"> • Mental health service delivery group • Mental health partnership board • Partnership Executive Group (PEG) • West Yorkshire System Oversight and Assurance Group <p>The Director of Adult Social Care has committed to stop the use of the term Borderline Personality Disorder in Leeds and to tackle the stigma associated with it,</p> |

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| | including a commitment to having services that communicate effectively, are more compassionate (including being trauma-informed) and are more coordinated. |
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Appendix 2: Index of Emma and Adam's updates

All Emma and Adam's updates are available at <https://healthwatchleeds.co.uk/how-does-it-feel-for-me-emma-and-adam>

| Video/ update title and link | Summary of content |
|---|--|
| Intro, June 2021 https://youtu.be/Av84EaEoknw | <ul style="list-style-type: none"> • Emma enjoys artwork, playing with her rabbits, playing Pokemon Go and is a talented musician. Adam is her main support and carer. • Has chronic migraines, mostly triggered by stress. • Living with autism and mental health issues in a neurotypical world exacerbates stress. • Ongoing Mobility and physical issues relating to incident related to mental health when not well • Current mental health diagnosis is recurring depression with episodes of psychosis. • Emma wants to take part in the project because of her desire to have a voice and get good support with her health, and to improve services for other people. • Adam sees the importance of collaborating with people who use services to improve them. |
| June 2021 Part one https://youtu.be/KX14myi5WoA | <ul style="list-style-type: none"> • How autism affects Emma's experience of mental health services • Experience of being labelled with Borderline Personality Disorder • Adam's experience of being Emma's carer and whether or not any support has been offered. • Lack of awareness amongst family carers that they are actually classed as 'carers' |
| June 2021 Part two https://youtu.be/BxgB3gAFjs8 | <ul style="list-style-type: none"> • Experience of the crisis team when Emma in crisis • Not feeling listened to • Experience of Community Mental Health Team (CMHT) – lack of co-ordination until in crisis • What would a good experience of a mental health service look like for you? |

| Video/ update title and link | Summary of content |
|--|---|
| June 2021 Part three https://youtu.be/iSifUVYUndE | <ul style="list-style-type: none"> • How living in Wetherby impacts accessing mental health services because of different trusts/areas offering different services • Difficulty getting transport to services in Leeds • Communication between different services is difficult when split across different areas. |
| August 2021 part 1 https://youtu.be/WnLcceEPa74 | <ul style="list-style-type: none"> • Positive experience of neurology appointment - Given options in written format to help process and given time to consider what she wants. • Autism support- adult social care assessment. Difficulties navigating and getting this and issues with having a carer preventing them getting it. • Positive experience of review meeting with CMHT. • Positive experience of feeling listened to by CMHT care co-ordinator • Experience of planning for discharge from CMHT • How joined up are services? Neurology/CMHT/GP • Mental health records not shared outside of region – difficult if live between areas. • Importance of information sharing/services being joined up. |
| August 2021 Part 2 https://youtu.be/xZ9R5nQo_RY | <ul style="list-style-type: none"> • Emma's ideas about keeping patients better updated about their appointments |
| November 2021 https://www.youtube.com/watch?v=JUxG2IDCBC0 | <ul style="list-style-type: none"> • Experience of Harrogate CMHT • Care co-ordinator left and experience of transition to new one. • Experience of trying to get help as mental health deteriorates. • Doesn't always feel listened to. • Carer involvement – Adam asked to leave appointment despite Emma wanting him to be there |

| Video/ update title and link | Summary of content |
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| | <ul style="list-style-type: none"> • Lack of communication about referral to Leeds Perinatal service. Doesn't understand why being sent to Leeds when rest of mental health treatment in Harrogate. • Bureaucracy causes delays that can have significant impact on people's mental health, particularly when in crisis. |
| <p>January 2022 part 1</p> <p>https://youtu.be/oVQFZ4QFyEM</p> | <ul style="list-style-type: none"> • Experience of migraine (neurology) appointment LTHT • Good to have choice between face to face and video call appointment. Sometimes video more convenient. • Experience of accessing carer support via Carers Leeds • Experience of phone and digital appointments • Importance of explaining clearly what will happen in an appointment |
| <p>January 2022 part 2</p> <p>https://youtu.be/EKNWBvsf4JM</p> | <ul style="list-style-type: none"> • Experience of perinatal service appointment – good care • Usefulness of asking patient to prepare prior to appointment to save time and help them • Involvement of carer in appointment • Mixed experience of communication about appointments • Importance of introducing where you're calling from and about what, when calling patients. • Issues of how joined up care is cross geographical boundaries and between hospital and mental health trusts |
| <p>May 2022 - Emma's experience</p> <p>https://youtu.be/Jm2TA4KYoKo</p> | <ul style="list-style-type: none"> • Harrogate CMHT, GP health check, Autism services, botox treatment. • Pleased with how her therapy has been working • Pre-discharge meeting coming up. Looking forward to this and feels ready for it (hasn't always been the case in the past, has been scary) • Services recently have been joined up between Leeds and Harrogate and between individual services – Emma thinks this is largely due to work of her care co-ordinator. |

| Video/ update title and link | Summary of content |
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| | <ul style="list-style-type: none"> • Good co-ordination contributes to how positive Emma feels. <p>Values when professionals feel really invested in me and my recovery, when it feels that professionals really care.</p> |
| <p>May 2022 - Adam's experience</p> <p>https://youtu.be/scLB67sr8fs</p> | <ul style="list-style-type: none"> • Adam's experience of Carers Leeds • Joined up working of Care co-ordinator CMHT who has considered needs of carers • Challenges accessing carers' support – would be good if there was more flexibility of when and how groups take place, particularly for those who are working full time. E.g. evening and weekend groups and option to access virtually. • When services are co-ordinated and Emma is kept into the loop, makes it easier and reassuring for Adam as her carer and he can focus on his job of helping look after Emma. |
| <p>June 2022</p> <p>https://youtu.be/E0F3T35F3kU</p> | <ul style="list-style-type: none"> • Good experience of CMHT pre-discharge meeting, professionals working together. • Felt let down by Crisis team who didn't attend pre-discharge meeting. • Very positive experience of care co-ordinator ensuring that things are joined up and that things are chased up. • Importance of preventative interventions to keep well • Much better experiences recently of Leeds and Harrogate working together as well as mental health and autism services working together. • Positive impact of compassionate care. |