**Emotional Wellbeing in Adults Born with a Cleft Q & A Transcript**

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With special thanks toRuairidh (CLAPA volunteer) who transcribed this Q & A.

Kate - Hi everyone. Thank you so, so much for joining us and for tuning in this awareness week for our live question and answer on emotional well-being. I’m the communications officer at CLAPA, and I’m here tonight with Kenny who’s our adult services manager. He’ll be chatting about cleft and emotional well-being. So we’ll be going through some questions, but also there’ll be space at the end for us to answer those so by all means write those in the live comments as we go along and we can address them at the end.

So I guess the first question to start with is, Kenny, why emotional well-being?

Kenny - Good question. First of all, hello to everyone. Thank you very much for joining us and tuning in, we hope you find this useful.

Some of you may remember, in 2018 we and our friends at Centre of Appearance Research did a big survey looking at whole of life experiences for adults, and it was one of the largest surveys of its type in the world. And with that data, myself and the team at the Centre of Appearance Research worked together to understand what the key issues were that had persisted for people into adulthood. And I think I naively thought it would all fit nicely together in one paper to report back to the academic community and the NHS to make a change that CLAPA could implement, and that health care teams could implement, and that would kind of be that really. But we found, what became clear very early on, was that actually there were a lot of different things happening for people, and that to do it justice, we kind of needed to do a lot more than that.

And we found that emotional well-being was a key component that might have been dismissed historically, and so we were keen to make sure that it got the attention that it deserved. And so that’s why it’s become its own paper. And we know that it’s a huge part of the cleft journey, yet mental health and emotional well-being has taken really until the last 5-10 years to enter common discussions. So CLAPA and awareness week wanted to make it a key focus this year, which I think is really great. And so tonight we’re going to focus in on the results, and give you some practical tips for your own life; be you an adult born with a cleft or the partner or family member, a parent, we hope that you can get something out of this, and that there’s something for everybody.

Kate - Definitely. So, as Kenny’s already mentioned, the Adults Whole of Life Survey 2018 looked at many factors in contributing to well-being in an adult born with a cleft lip or palate. So, Kenny, can you tell us a bit more about this survey? Its questions, how you went about bringing the responses together, and a brief summary of results?

Kenny - Yeah, certainly. So I brought a prop along which some of you may recognise: the paper version of the survey. Most people actually filled it out online, but this just gives an idea of how comprehensive the survey was. 54 pages. So, you know, there’s a lot to it, and we are incredibly grateful to everyone who took the time to complete it, because as I was saying before, we got a huge wealth of information which has been incredibly useful.

So in this survey, the reason it’s so long is because we tried to think of every kind of area of life that cleft may potentially impact, and did our best to include that in the survey in one way or another. So be it emotional well-being that we’re talking about now, be it people’s surgical experiences, orthodontics, speech therapy. All the kind of more obvious stuff to perhaps the less obvious stuff, such as what people do for work, and what their educational experiences were like, how they would rate their friendships, what their romantic relationship experiences have been, and intimacy. And all those sorts of things that are so intertwined with, you know, your experience but perhaps we don’t think of it at first glance.

As a result, we had a mixture of question types to elicit the sort of information we wanted. So we had a mixture of multiple choice as well as shorter answer questions. But what was also really important to us was that we gave everybody the opportunity to tell us anything that they felt we hadn’t given them the chance to cover. And what we found in those kind of free text boxes was that people shared very personal and emotive stories which we very much felt, particularly myself and my colleague Nicola Stock from the Centre for Appearance Research as we were going through these, we very much felt a duty to do something with this. That people had taken the time to share their most personal, most difficult in some cases, experiences. And so we didn’t want to waste that, you know. We wanted to make sure we did something good with it. And so, we had over 250 responses to the adult survey which, again when you think of the size of this thing, that’s pretty good. And we ended up with 207 final responses which we could use.

So we found that there were 4 key areas, which were: emotional wellbeing (which we’re talking about tonight), physical health (which is peoples’ breathing, speech, hearing, other common conditions), their social experiences (which are things like work and relationships, and of course that’s so intertwined with emotional well-being that we can bring some into the discussion tonight as well), as well as medical decision making (so that’s peoples long term discussions about whether they return for treatment and how they go through that thought process). So as we were saying out of those main areas we’ll talk about emotional well-being today, because we found that’s a significant factor for people. Around half of adults have received a diagnosis of anxiety or depression which is higher than average. And we’ll talk about that during the course of the evening as well. But it’s worth keeping in mind that the cleft population are more likely to be identified because they are under the care of a psychologist. And it’s worth bearing in mind as well that those that reported a medical condition felt that cleft was partially responsible for that. So I think that’s a key finding from the survey, that a smaller number felt that their cleft experiences were primarily responsible and then others felt that there was something else that happened in their life that was more likely to be directly responsible for that.

Positively, most people were receiving at least 1 form of treatment and the vast majority of people felt that psychological support was a vital part of the cleft treatment pathway. And we know that it’s a recent addition in the grand scheme of things to cleft care, and so it’s worth bearing in mind that the adult population predominantly actually haven’t received psychological care. So it’s really come into common discussion in the past 5/10 years, it’s come into cleft care within the last 20 years, so prior to that people wouldn’t have routinely received psychological care. So it is worth considering, particularly if you’re a parent listening to this, it’s likely your child’s experience could be very different as a result of having that psychological input from an early age.

We know as well that in our group of people that completed this survey, that self-esteem seemed to be something that had been impacted by their cleft experience, and I think a lot of international research would agree with that finding. And I think it’s worth bearing in mind that self-esteem is something that fluctuates for all of us from time to time, and we all have a sense of self-esteem, higher or lower depending on what’s happening in our life. But when that drops below a certain threshold, that’s when we’d class that as low self-esteem. That’s where someone might not see the value in themselves, or might not see in themselves what other people see in them, which obviously is a real shame. And we found in this survey that people’s self-esteem was generally lower than that of the general population, which as I say is in line with other research. But the positive is that we know that now, and it’s something that we can do something with, which is what this is all about.

Kate - So we’ll be going through all those points that Kenny mentioned, so thanks for that really good introduction Kenny. But to start off we’ll talk a bit more about that result that we published on our infographics. So the survey found that almost half of the current sample of adults with a cleft lip or palate self-reported a diagnosis of a mental health condition. For example, self-reported depression rates were higher in this survey compared to general NHS figures. So why might this be?

Kenny - Yeah, well first of all I think it’s worth acknowledging that those numbers are particularly high, and I can certainly see why on first glance those numbers might be concerning. But I think it’s really important that we unpack that a little bit and explore some of the reasons why we might be seeing that come through.

Keep in mind now that people are seen now by a psychologist, as part of their cleft care. So any adults as well that have returned to the system, which we found from the survey was quite a lot of them, will now be under the care of a psychologist. So although they weren’t under the care of a psychologist for the first however many years, at the point that they returned to treatment, they now are. So they will get diagnosed with those conditions if they’re presenting with them. What we know, therefor, is that because people are being seen by a psychologist, nowadays 100% of cleft population get seen by a psychologist, we know that they are more likely to get diagnosed with a mental health condition, because what we also know is that in the general population mental health conditions are widely underreported, because lots of people don’t have access to the psychological care that the cleft population does. And we’re actually, you know, very fortunate in that regard that people are therefor being diagnosed earlier compared to the general population who aren’t having access to cleft care. So that’s one factor.

And then obviously people who reported having a mental health condition, as we were saying before, the vast majority were receiving support which would suggest within the cleft population, actually mental health is becoming somewhat destigmatised. And we can see that even in the context of the survey where the group of adults… I think if you were to take that same sort of age range across the general population, we wouldn’t see as many open discussions on mental health. So actually, I see that as a real positive, the fact that people are talking about it and that people are feeling more empowered to seek the support that they need. Because we know in the general population that we’ve got figures that the NHS will put out, but actually it’s quite likely that it’s actually closer to our figure than it is the published figure that the NHS has put out.

What we can’t ignore, though, and it would be unwise to ignore, is that cleft is going to be a risk factor for mental health. And that is why, that’s exactly why we have psychologists on the cleft team because this isn’t new news to us. And that we know that support early on in the treatment journey is important. And it’s worth remembering, as well, that anxiety and depression are normal reactions to an abnormal situation. And we know that when people go through a traumatic experience they are at a higher risk of having psychological impacts from that. We know that cleft is an abnormal situation in the sense that it’s not something that most people have to go through or deal with in their lives. So it is a unique set of circumstances that comes with a unique set of challenges and I want to acknowledge that and not down play that. We know as well that the current pandemic situation is another example of an abnormal situation and we know already that its impact on mental health is something that we are already thinking about. The true mental health fallout from what’s happening now, COVID-19, is something that won’t show for many years. But we know that it will, and the impact that it has will be far, far greater actually than a number of people that get sick or die directly from COVID.

So, there’s no inherent weakness or inability to cope in the cleft population. It’s just that being born with a cleft, I think it’s important to point out, doesn’t make you mentally weaker and in fact to the contrary many people have said that coming through and out the other side of the cleft experience has given them a sense of resilience and that they may be better able to cope. And actually we’re seeing that, in our community at the moment in these trying times, that actually for a lot of them this is something that perhaps they are taking in their stride, more so than others in the general population. Because they have that reference point that life is uncertain sometimes, and they’ve got the skills to deal with that.

Kate - OK, thankyou Kenny. So before I read out the next question, just want to say hi to everyone that may have just tuned in. Thanks very much for joining us. As we mentioned at the start, if you do have questions feel free to ask them in the comments and we’ll look at those and address those at the end. So thanks for tuning in and for sticking with us. We’ve talked a lot about the importance of psychology in cleft care. So what are some of the common things that impact on emotional well-being that are related to the cleft journey?

Kenny - So I think it’s more than people might think, it’s very multifaceted. If we start at the most medical level first of all. You’ve got people coming to terms with medical treatment and change in appearance, and things like that which is enough to have on your plate and to get your head around. And as anyone who’s gone through a significant medical procedure knows, there’s a big element of psyching yourself up for that as well, and that is something that the cleft teams will do a lot with and that the cleft psychologist will make sure that people are ready for. And they do really understand the impact that that has on emotional well-being, as well as the uncertainty and questions about the recovery and all those sorts of things: the impact on time out of school, work, university, whatever it is that’s important to you. And also acknowledging that for lots of people the concerns there are not necessarily what might seem obvious to someone looking in from the outside. So while there might be an assumption that someone’s really concerned or has some fear around the surgery, it may be actually that they’ve got (this is something that came up a lot in the survey), that the bigger thing is actually a needle phobia that is part of the anaesthetic. And that is actually what people are concerned about but don’t feel that comfortable to raise. And so the cleft psychologist will help to coax that out of people. It’s really important that they do, because there’s actually stuff that can be done about that. So for example, if someone may be concerned about like a needle phobia, there’s other options you can have for anaesthetic that don’t involve a needle when you’re still awake. And so being able to unpack that with people and go through and address those concerns is really important. So that’s at a medical level of the impact on emotional wellbeing, and what the cleft team psychologist can do to support that.

Then there’s, like we mentioned before, peoples’ perceptions of themselves which looks at things where self-esteem may be impacted. That can be someone’s perception of how they look or how they sound, any speech concerns they might have. And research will tell us that if we perceive our own appearance or speech as different from whatever we consider normal to be, then this has a negative impact on our self-esteem, and we assume quite wrongly often that others may view us in the same way which we know is often not the case. And we’re all, I think anybody can relate to this, we’re all our own toughest critic. And that goes way beyond the cleft world. But that is not to diminish that this is a hurdle to be overcome, but I hope you can take some comfort in that actually for most people at some point in their life, they will feel that way. And sadly for some people, and we know that this does happen in the cleft community as it was discussed on the road shows, it’s come up in the survey, it comes up on the Facebook page from time to time as well, that sometimes other people may have fuelled that fire, particularly earlier on in life, by making comments about appearance or speech which lastingly stick with people and may have an impact. And as I was saying a lot of that can happen in early life.

But what we do know is that if that is left unchecked and you continue to believe those thoughts, that those experiences can obviously have a profound impact into adulthood. And this is at the heart of our findings, really, that if we build psychological care in early as happens nowadays, so those experiences are able to be unpacked at the time rather than bottled up and hidden away and then they come up in weird and strange ways much later on in life where it actually has a much bigger impact, then we can have a much more positive outcome for people. And I think, you know, we do have an amazing ambulance at the bottom of the cliff for people, but let’s build that fence at the top so that we don’t need to use it.

Kate - Yeah, absolutely. So you just mentioned that both perception of appearance and of speech can affect self-esteem and emotional well-being. So, in what kind of ways did these things have an impact?

Kenny – Yeah, so we know that key to our self-esteem is our perception, and so over time it becomes important to recognise how we perceive ourselves versus how other people perceive us. Because I honestly believe that we are often harder on ourselves than we should be. And as we’ve been saying, it’s generally something people struggle with. I think one of the nicest quotes I can think of here that I heard people say when it comes it to self-esteem, because it is something that we all go through, I think, from time to time. And I’m certainly no exception to that and I can pull on my own experiences here. I know that sometimes the way I perceive myself is not how others perceive me. And I had a good friend fairly recently saying, “your life would be a lot easier if you just saw yourself the way I see you and the way that everybody else sees you”. And it is so true, but that is a lot easier said than done. And it’s not a case of switching on a tap and you can view yourself in that way. And we know that it changes over time and you can have good days and bad days with this.

But specifically looking at appearance and speech, we know that if this is different from what the norm is considered to be, and that this may impact on self-esteem, because you may feel that other people notice it, whether they say something or not. And that can be born out of early experiences and comments in life, and generally by adulthood people won’t comment and actually generally by adulthood they don’t notice in the way that they might have earlier in your life. But in the back of your mind that perception question that others may judge you can still very much be there. And we understand that very much for appearance. W can see plenty of examples of that in our culture and our media. I would go so far as to say there’s a global obsession with appearance and a huge value placed on appearance. We are starting to see that change a bit, but we actually still know that there is a very narrow beauty ideal and that the vast, vast majority of people, you know probably >95%, don’t actually meet that. And so huge numbers of people, again the vast majority of people, feel inadequate in some way. And it’s worth pointing out, even people who fit within that will have something about themselves that they feel insecure about, we all kinda do when it comes to appearance. But when you add on top of that natural human concern about appearance that an appearance difference as a result of cleft may be even less understood, you can see how that would impact on self-esteem. And it’s worth pointing out again, this is not in all cases. Some people are very confident, and what we want to do is empower everybody to get to that stage where they feel confident in who they are and in their own skin.

Speech is slightly different again, because it’s not something actually that your average person is particularly aware of. I think we’ve seen a lot of campaigning around appearance, and people generally are coming to accept that you don’t judge someone based on their appearance, that’s a wrong thing to do. But if someone hasn’t had difficulties with speech in their life, it may well be something that they take for granted. And so while we are getting through feminism, body positive movements, all those sort of things that recognise peoples appearance and peoples value and not making value judgements based on appearance; we actually haven’t seen the same attention on speech, and we know that it can be quite stigmatised. So if you sound different, sometimes people make assumptions about you which we don’t see so often anymore with appearance. So if you have a speech impedance without an appearance difference, which is often the case for the cleft palate population, it can be harder for people to understand this and therefor easier to make some of those negative assumptions. And we know that speech is very important in many settings as well. So in the workplace it’s a key part of many roles: you might have to talk on the phone, which could be quite anxiety provoking if people perceive their speech as different, and there’s no huge research on that right now.

And I’m quite keen actually to explore that further, and particularly at the moment in the situation we find ourselves in globally. These feelings to do with appearance and speech may well be heightened for people because none of us enjoy hearing our own voice or seeing our own image, because we are our own toughest critics. And what are we all doing lots of at the moment? We’re all doing these video conferences as part of our work life and social life, so we’re hearing our own voice, seeing our own image all the time, and for some people that can be quite confronting and disconcerting. And so I just wanted to acknowledge that and the fact that everybody else who is on a video call is far more interested in their own appearance and speech than yours. So that’s worth keeping in the back of your mind as well. So yeah, in answer to your question, these perceptions can impact on self-esteem and they may also impact on certain opportunities. People have mentioned certain elements of discrimination in the workplace more so because of speech over appearance. But there have been examples of both, despite the UK’s anti-discrimination laws.

Kate - Absolutely. Thankyou everyone for your comments, we’re seeing some come in. So we’ll definitely look at those at the end, so keep asking if you’ve got any questions. But for now, Kenny, would you mind talking a bit more about… You just mentioned workplace discrimination, so could you mention some common workplace discrimination experiences that people sort of addressed in the survey, and what can be done about this?

Kenny – So I guess, to begin with at the most extreme end, you have workplace bullying, which is a very direct attack on somebody in the work place and is a huge problem generally. And it’s been identified as one of the biggest, if not the biggest, health and safety risk in modern workplaces today. And that can take many forms, you know. Obviously you can think of what overt bullying looks like: name calling, physical aggression, it’s those sort of things which we often see at school and things like that. We don’t so often see that at the workplace, but what we do tend to see in the workplace is more subtle forms of bullying. And that doesn’t usually consist of name calling or teasing, but it may be a lack of opportunities, it may be somebody not giving you the credit for the work that you do, or not being valued or recognised properly, not being given a pay rise where others are, those sort of things. And it’s important to point out, it’s not necessarily bullying just because you didn’t get a pay rise, that isn’t inherently bullying. But if you perceive that you’re being treated differently as a result of your cleft or actually of any other factor, that isn’t related to your work performance or your work position, then that would be discrimination and you would probably have a case to raise that further.

In the UK… The UK have some of the strongest laws in the world on this, and such discrimination is illegal. It’s not to say, of course, that it doesn’t happen. We know that it does. But every workplace is required by law to have processes to deal with this, and in theory the policy may and in some workplaces will work really well. You know, speak to your manager or to human resources. But you quite rightly can have the question: well what do I do if I’m being discriminated against by a manager? And actually we know this is one of the more common forms of work place bullying, and its actually not generally your colleagues but it usually will come from someone higher up than you. And that’s obviously a really difficult conversation to have with a manager if you perceive that they’re bullying you. So I would recommend that you get advice from somebody you trust, ideally a colleague within the workplace who can see what’s happening and be a bit of an ally and help you take some steps to remedy that. But if not, if you don’t have someone in the workplace that you feel you can talk to about this, then consult your family, your friends, your partner. But also the UK government guidelines are really clear, and there is a mediation service available which can help you with workplace grievances. And they can independently, if required, investigate what’s happened, and make recommendations for the work place and support you. So that’s kind of workplace bullying.

Other people may pre-empt discrimination, and I think this is worth having a conversation about. So you may well be working in a workplace where you’re not experiencing discrimination, but you pre-empted that you might. And so some people might choose, and we saw this come through in the survey a lot, so some people may choose work in an area that they feel they may be more accepted in than other areas. So it may result in people not actually taking their dream job and settling for another line of work or working for another organisation because they feel that they’ll be treated better. And obviously that is concerning for us, because someone may not be reaching their potential or having this high level of job satisfaction that everyone wants. We know that we spend lots of time normally at work, and so it needs to be something that’s important to you, and ideally it should be something more than something that pays the bills. And it’s a real shame actually to see people missing out on this, out of fear that they might be discriminated against. And so in this scenario if you feel that there’s something you want to do with your time but you’re not doing it out of fear of reaction or consequence from certain people, then that is something you can talk to the cleft team psychologist about. They’re experts. They’ve seen it before, and they can give you strategies to work through how your feeling and hopefully give you the confidence to feel empowered to do what you want to do. Because, the only shame with all of this would be to miss out on life.

And there are other things that may come into this as well, like a lack of emotion, or where people feel that they’re on par with their colleagues but because the role involves speaking, for example like maybe chairing a meeting in a managerial role or giving presentations to other companies, people feel that they’ve been overlooked for those roles because of their speech or appearance. Which obviously is not only unfair, but it’s illegal. But unfortunately it can happen. And it’s not necessarily deliberate. I think it’s key to keep in the back of our minds that we know that there is unconscious biases out there, which is when people make assumptions based on characteristics of somebody but don’t recognise that that’s what they’re doing. And that can be prevalent particularly at the interview stage. It tends to be less of an issue once somebody gets to know somebody. But it’s the result of peoples own world view and perception of something, rather than what you bring to the table. And so my advice for employers is to be really clear as well as why you’re turning them down, and if you’re not clear on that yourself then you need to go and have a think about if this person is qualified for the job then why am I taking this person over that person. You need to be really clear on that. Not only because that’s what’s legally required of you, but that helps you get the right person for the job which ultimately is your aim when you go out to recruit. Recognising as well that going to an interview for anyone is a big, big undertaking, and to not be successful is more often not a reflection on you but it’s actually a reflection on the other strong candidates that may be better suited for the role, may have more experience.

And similarly, if you feel you’ve been discriminated against through unconscious bias, which may not just be because of cleft, it may well be because of other attributes as well, it’s worth recognising that unfortunately these things are accumulative as well. So if you have more than 1 attribute that may make you more vulnerable to unconscious bias, they can be exponential. They can add on top of each other. So again, if you feel empowered to do so, raise this with a potential employer; but again, if you don’t feel comfortable, go through the government support service to raise the issue of unconscious or perhaps even blatant bias.

And finally, it’s worth pointing out that for a lot of people, their work experience was actually a really positive thing. I don’t wanna make it out that you’re going to have problems at work. A lot of people expressed that going to work was a really positive experience and they were really proud of what they’d done in their career. So although we saw some people, and sadly overall reported they felt less proud of their work, we did see a significant number of people who actually reported work to be a really positive thing and that they were proud of their career and what they had achieved, and that for many people the work stories were really positive. They had made good friends, they felt really connected to their workplace, so that’s obviously what we want to work on and to see for more people. And I know that in the adult services project later on in the year when we can do a bit more things in the community again, this is an area that we really want to do more with.

Kate - Yeah, thank you for going in to that Kenny. It’s a really important conversation to have. So obviously you’ve talked through how people might have been perceived in the workplace and how this can affect how they view their own job prospects and themselves. But did you also find that the way people view themselves had an impact on their personal lives too?

Kenny – Yeah, I mean the short answer absolutely is yes. To unpack that a bit more, so we did see that people’s perception of themselves and their past experiences with others can impact on their personal life. And its reasonably fair to say, the more discrimination that people have faced in childhood, you know, this has an impact on how they approach relationships in adulthood. We know from all the psychological research into attachment and childhood and things like that, we know that if people’s relationships early in life with parents and family and friends are not as positive, that it’s likely to impact on them later in life. So in that sense the cleft population is no different. And we saw a really varied response when we asked some of these questions.

So we found that a lot of people reported really positive relationships with parents, had some really good friendships growing up, and that’s a really protective factor and it translated into positive relationships in adulthood with many people reporting that they found their best friends at university or at work, which is a really nice thing. And I think it goes to show that although, and there was a theme of this, although school years might be tough for some people, actually generally things like university were a really positive experience because you suddenly find yourself surrounded by like-minded people for the first time in your life. And that’s incredible empowering in itself. But others they found that starting friendships could be difficult, yet they reported being happy with those friendships once they had established them. And for a smaller again number, but again a significant group that we don’t want to downplay, establishing friendships was really difficult and they didn’t rate those friendships particularly highly once they were established, which is obviously not something that we want to see. It tended to correlate with specific events in life which we wouldn’t necessarily attribute to cleft either, but I think it’s important to point out that this is an example of life’s patch work quilt if you like. Having a cleft does not make you immune to the rest of stuff, other things that can happen in life, you know, all those other trials and tribulations, and it does add on top of that. And so to acknowledge that for people, that can make things even more tough than they might otherwise have been.

One area that very routinely for nearly everybody, and it seemed to be regardless of how they got on with friendships, it seemed to be more difficult for our population than it was for the general population to establish romantic relationships. And there are some reasons which I think I can offer for that from what we’ve seen, and it’s something that we’re looking at in more detail at the moment. I’m working with Bruna Costa at CAH to unpack some of this a bit more, to look at risk and protective factors and “if someone answers this is it going to make them more likely to answer this in the survey”, and I think we’ll get some interesting info out of that. But it seemed to be a bit of a higher stakes game, people perceived it was higher stakes to establish a romantic relationship than it was to establish other types of friendships and relationships. And so what we generally tended to see was a delay of a number of years before people found someone that they felt comfortable to have a romantic relationship with.

So overall, we found that on average people with a cleft have fewer romantic relationships compared to those that weren’t born with a cleft, but there were some positives in that. The positives were that people generally reported that those relationships tended to last longer than the general population, and actually when we did the maths on it, it was significantly longer. So of people who had been in a relationship, the average time in our survey that people had been in a relationship was 14 and a half years. In the UK, the general population average for the length of a relationship is 2 and a half years. So I mean that’s quite significant. It suggests that there are some benefits in taking that extra time to find the right person. And, as I say, far fewer relationships: on average our group had fewer than 2 relationships, whereas I can’t remember off the top of my head what the UK average is but it’s greater than 10. So there was quite a disparity in there.

But although there was a lot of concern among people who either hadn’t experienced romantic relationships or who had experienced one that ended, again as many people in the general population do, people who were currently in relationships, whether that was marriage, civil partnership, cohabiting or dating, they reported a higher level of satisfaction and they used phrases such as they were greatful for their choice and their partner, and commented on the fact that they’d made a conscious choice to wait for the right person to come along and enter their life, meaning that they actually didn’t go through a lot of the heartache that they might appear to go through. So there’s definitely 2 sides to this story. And people also reported learning to become comfortable with their own company and being happy to wait, and I think we can all think of people in our lives who just cannot be single and just constantly bounce from one relationship to the next. Generally actually what we were finding in our population was that for most people, they were OK with their own company for a bit, and to actually figure out what they wanted out of a relationship rather than feeling this desperate rush to get into one.

But that being said, because everyone is different, still a small but significant minority were experiencing unhealthy relationship situations. And when we analysed these deeper by asking some quite specific questions in the survey, unfortunately it came down to self-esteem in most cases. What we tended to see was that people had a sense that they weren’t good enough for their partner, and as a result they would stay in a relationship that they were unhappy with simply because they felt that they couldn’t do any better. And I think you don’t even need to point out that that’s a sad situation when that’s happening. Because any loving partner shouldn’t be making anybody feel like that. And in the adults roadshow in 2018, I actually spoke to lots of partners, one of the really nice things was that lots of peoples partners came along to support them which was lovely, and they all said much the same thing which is that they don’t see the cleft in the way that their partner does. They acknowledge that it’s part of that person, but they just see their partner who they love for so many reasons, and that’s part of what makes them who they are and, you know, it adds to the person. It doesn’t take anything away from how they feel about the person.

So I wanted to share that and to remind people that it may also be your own self-perception rather than how your partner actually perceives you. So yes, peoples’ perceptions of themselves, to summarise, seems to be a key factor in how they approach relationships. And the barrier with that may not actually be cleft related specifically. It may be that it’s impacting on your confidence and that it’s the lack of confidence to approach people that is the reason you feel you’re not getting anywhere with relationships, rather than people not being interested in having a relationship with you. Because they’re actually quite different. But unfortunately we also know that that becomes a self-fulfilling prophecy unfortunately. So the lack of self-esteem and confidence to approach people and engage with people then will make it hard to form a new relationship and make a positive first impression. But again, the good news for most people was once they had established friendships or romantic relationships they reported that high level of satisfaction and that they’re more meaningful perhaps than they might have been had they not gone through the journey and gained that experience along the way.

Kate – Yeah OK, thank you. So once again thanks to everyone that’s still tuned in, and if you’ve been following us along so far through when we speak on our social media, you might have seen that we’ve been sharing videos from some interviews with some really incredible young people. So we shared one today and something that came out of all those interviews actually was the importance of relating to people and how difficult it can be growing up when you feel like you can’t relate to others who aren’t going through the same thing. So a really important question that comes from that is, how can we as friends, as partners, as any loved one, best offer support to those who are directly affected by cleft if we’re not affected or if we haven’t been through the same thing.

Kenny - I’ll start by acknowledging that that’s a really good observation and something that can feel very tricky. I think we can all think of times in our life where we felt like we were going through something that nobody else understands. And the reality is that that may sometimes be true, however it doesn’t mean that other people can’t empathise with you. And you don’t necessarily need to have gone through the exact same experience to say and do the right thing at the right time. We’re simply too scared of getting it wrong, I think, as friends and family. So what I would encourage is to find some common ground and common experience that gives you an idea of what your friend or loved one may be going through. Because we all do have life experiences we can hinge things off. I think part of the human condition is that we go through different crises from time to time and gain new life experiences and perspectives from that. But equally I think its fine to say, “What you’re going through sounds really tough and I just don’t quite know what to say.” I think sometimes being able to acknowledge that and being genuine in that and just being there to be a good listener and being prepared to learn is actually more important than trying to find the right words to say. And I think this goes for everything and for anything really. I mean, you can think of your own friends and picture a tough time and picture emotions that get attached to that and how it might feel and how sometimes its best to say nothing but just be there for your friend. Be prepared to listen and see what they have to say and just let them know that you’re available for them.

The other thing I’d say on this is to not under estimate the impact of seeing your friend go through a tough time and to not feel bad about that. As we were saying earlier, going through the cleft journey isn’t something that most people have to do. And it has an impact on you as a friend or family member. We get that. That’s why our parent support service exists. We know that watching your child go through this is a huge thing. Therefore, it’s not really any different than watching your good friend go through this. Of course it’s going to have an impact on you, and that’s absolutely OK to acknowledge. And I remember my friends saying this when they saw me going through jaw surgery. They had some quite strong feelings around that at the time. I think it took them back a little bit, because I suppose most of the time they were used to seeing me happy, healthy and well. And then suddenly they were looking at a very different picture for a little bit. And I think it made them feel both sad that they had to see me go through it, but they also mentioned later on that they had a sense of guilt that they were able to leave the hospital and go home at night. And they felt as well that they didn’t feel as though they could have that conversation with me at the time, because they felt that how they were feeling paled in comparison to what I was going through. But actually to be honest with you, I would have welcomed that discussion and that conversation. Because I think it really would have felt then that actually I wasn’t going through this on my own, we were all going through this together as a friendship group. So I would say that that shared friendship experience has definitely strengthened those friendships. I mean, the good times feel even better now because we’ve gone through that together. So I would say don’t be afraid to own how your feeling and talk to your friend about that, whatever side of the equation you’re on. Because as I said, it’s a normal response to an abnormal situation.

Despite this, though, we also know that there is no replacement for somebody who has walked in your shoes and fully understands the journey that you’re on. And that’s where CLAPA really comes into its own. Because that’s a perspective that we offer. I was mentioning before the parent support service, and we’ve also got our peer support service which people who have gone through the journey can offer their perspective as well. And that can be a really positive thing if you’ve got some really specific questions and feelings that you would like addressed. And if there’s a sense that what is lacking is a real understanding, then please turn to that for support because it’s a great service.

Kate - Yeah definitely, and that’s the message that CLAPA generally puts out time and time again: you’re not alone and there are always people here to support you. Wherever you are on your journey, whether you’re a patient, parent, friend, partner, anybody… So yeah, really, really important to talk about. So on quite a positive note, from the survey, as you already mentioned, a lot of people said that their clefts had made them stronger, more resilient, and people also listed some of their tips and tricks for when they’re having a challenging day. So obviously given that millions of people around the world right now are living in lockdown, it’s a pretty relevant question. So, what are some things that adults mentioned in the survey which helped them with their emotional well-being?

Kenny - Yeah, definitely a strange situation around the world that we’re all in together at the moment. But as many people who have been on the cleft journey will have experience with, being stuck at home is not necessarily a new thing. It’s something that we all go through after surgery. Obviously you spend a bit of time in hospital, then you’ll be discharged to recover at home. And what do you do? You spend a few weeks on the couch watching Netflix and it’s for all the same reason, it’s to prevent getting an infection. So for a lot of us the difference this time around is 2 fold. Hopefully the vast majority of people this time round are not unwell, you’re doing well so your able to view that time a little bit differently. But the other thing is that your also going to have other people around at home in many cases. Now, we’ve seen on our Facebook page the positive things that people are doing during lockdown to make a positive situation out of this. That being said, this is still new for a lot of people including many people in our community. And a lot of things that people said they do to look after their own emotional well-being in the survey are things that we can quite safely and easily do in lockdown. And it’s all about us finding what’s right for you.

Being able to talk to other people about how your feeling, and obviously if you’ve got others within your home bubble that you’re able to do that with and you feel comfortable talking with them, then that’s a great place to start, and we know that reaching out to people is incredibly important. If people live somewhere else, you can still pick up the phone and have a chat. Don’t let that physical distance cut you off. I think in the early days of this we called it social distancing, but we’ve changed the words to physical distancing because it’s important not to be socially distant. And in the same way we’re having a chat now, Kate, you can do that too at home and have a chat with others about how you’re feeling. And it’s important that we can all identify somebody that we can have a chat with; you know, it’s really important.

Something else that people found really good for their wellbeing is regular exercise. And again, that is something that you can easily and safely do either in your own home, there’s things like yoga and meditation, but equally getting out and going for a walk. There’s nothing wrong with that if you’re keeping your distance and keeping within the guidelines, or going out for a run or a bike ride or a swim at the beach if that’s something that your able to do. Obviously it’s not the time to take up a new sport, if you’ve never gone surfing before now’s not the time to learn. But the things you do and enjoy, keep them up. It’s not only going to keep you emotionally well, but it’ll keep you physically well too.

There’s lots of things you can do to relax at home as well. People mention things like putting on a film, reading a book, whatever it is that’s your go to, there’s no right or wrong answers here. A lot of people mention listening to music as well as a way of getting through. Music can talk to them in a way that people felt really resonated with them. And also in a way that they might not have been able to articulate themselves, but a song can often do that perfectly, which is a really great way to actually start a conversation about how you’re feeling with somebody else. You can take a song that you feel really means something to you, share it with somebody, and ask them what they think. So have a think about that, what songs do you find connect with you when you’re in different moods and at different times. So there’s lots of fun things you can do with music.

Some people felt really guilty about this, and of course there are some circumstances where this could be problematic, but for most people if you enjoy a glass of wine or a bit of chocolate or you want to bake your favourite biscuits, you know, anything in moderation should be fine. So whatever it was involving like food or drink, it’s all about getting through, and if it makes you feel better emotionally then as long as it’s not creating a major problem for you in other ways, then I would suggest going for it.

If your biggest achievement today was putting the rubbish bins out, then good for you, that’s fine. We’re in a very strange situation as well and I think that’s important to acknowledge. And we can’t judge ourselves by our previous productivity. The world that was there 2 months ago in which we kind of judged ourselves by actually doesn’t exist at the moment. So it’s really important that we be kind to ourselves and that we don’t judge ourselves. And I hope that if you’ve taken nothing else out of this talk, it’s that you’ve taken the message to not judge yourself by how you perceive others to be doing. And also by the same token, avoid judging others by how you perceive yourself to be doing. Be kind to yourself, be kind to others, and cut yourself some slack. It’s ok to be doing whatever makes you feel the most comfortable.

Kate - Some very good advice and an excellent round up there. So I think this will be the last question just so that we have some time to address the ones you’re asking at the end. So I guess the big overarching question is, why is it so important to talk about emotional well-being for adults born with a cleft, and what does CLAPA do to offer support?

Kenny - Well again, I hope if we’ve demonstrated nothing else, it’s that emotional well-being is important for everybody in our society. We all have to look after our emotional well-being. We all have mental health, and we’re recognising that more than ever now. And I’m sure we’ll all have a think at some point as we start to come out the other side of this current situation of what do we want the world we go into next to look like. And I would hazard a guess that it’ll look a little bit different to the world we had a couple of months ago. And I hope it’s one in which we do find a bit more compassion and kindness and time to connect with each other and really understand how each other is doing and feeling.

In the context of cleft, obviously we’ve come on leaps and bounds in recent years in recognising the impact. It’s not just the physical and medical journey, it’s not just the impact that that has on people, but it’s the long term psychological impact of going through something that is as unique and challenging as cleft. We know that what we’ve found in our survey in the UK is by no means unique. There are examples of studies in Scandinavia, USA, China and Australia which have all found the same concept that emotional well-being is impacted in some way by cleft and that there are things that we can be doing early on in life to set people up in the best way to live a happy and healthy life.

Historically, and wrongly, there has been a lot of stigma about acknowledging mental health, which when you think about it, makes no sense. We all have mental health. And mental health is a spectrum that we all sit on, and we move up and down depending on what happens in our lives. As a society we’ve come a long way in recent years to destigmatise mental health and to acknowledge it as just as significant a condition as one that would impact on physical health. And I know that sounds absurd, but if your leg was hanging off you wouldn’t just wait and see what happens. You’d go and get help for it. And it’s a shame to think that the same attitude still doesn’t apply to mental health. And that’s why it is incredibly important having cleft teams with psychologists, because they can notice early on that your leg might be starting to hang off, and actually do something about it before everything becomes too much. And what we’ve recognised by talking about it and by addressing things early, is that we can keep people at that more positive end of the spectrum where people are happy, people have a high level of self-esteem, and people are less anxious about the future. And not only less anxious, but also excited about the future because that’s important too. And as a result of that they’re making the most of life. And that’s what we want to see for everybody. And so yes, acknowledging that cleft does present some challenges, but it doesn’t have to be a barrier to leading a full and happy life.

And that’s where CLAPA and cleft teams come in, to make sure that everybody is living their life to the highest potential. And it think between CLAPA and the NHS cleft teams and our partners like the Centre for Appearance Research, we’re a pretty formidable team. And we acknowledge that everybody in life needs support from time to time with something. And so what CLAPA do to offer support is that we offer the opportunity to engage with other people who have walked in your shoes. Whether that be through events, you know get together and things with your communities, adventure days, and weekends away. But we also empower you to understand more about the condition that you or your family member has been born with and we do that in a variety of ways. We break down the barriers to accessing healthcare info. So to use that adults project as an example, we’ve delivered our cleft talk podcasts and videos where we’ve taken some of the most frequently asked questions that people have but didn’t feel comfortable to ask, and then we’ve put the experts in to answer them, and then people can listen and watch in their own time. And we’ve found that’s been really successful. In a similar vein, we’ve had our adults annual conferences and previously our wider CLAPA conferences where we’ve looked at issues you’re telling us, areas you want to learn more about but don’t know where to turn to, and we’ve brought that information to you as well. And finally, as we mentioned earlier, we have our direct one to one support which is our parent and peer support service, as well as our info email support service, and then the group support that’s offered through our Facebook groups and social media pages.

And we acknowledged that many adults won’t have had access to psychology services growing up as we mentioned before, and may feel a real sense of loss about that. And while sadly we can’t undo the past, we can start here and have a positive way forward which is why adults of any age are entitled to visit their cleft team, even if they’ve never seen that cleft team before. In fact, much of the work that the cleft team psychologists do is to support adults who have never had psychological care previously. So there is no need to feel alone, and there is nothing that a cleft psychologist hasn’t seen or heard before. Again, the only shame of all of this would be the shame of missing out on life, and there are always people who can support you on this journey, and I think that’s kind of where I’d like to wrap up on this.

Kate – Yeah definitely. So I think now we’ve got a bit of time to look at some of the questions people have asked. Thank you so much for watching and listening, so I’ll read out some questions for you Kenny.

A question from Rebecca. She says, “I’m trying to raise my son to be cleft proud. Any tips would be appreciated.”

Kenny – A great question, Rebecca, and I think the fact that you’re thinking about that means you’re already in great stead to do a good job. I think, first and foremost, having the same expectation for your children as you would if your child didn’t have a cleft is important. Letting them know that you don’t see cleft as a barrier but it is a part of them, and to acknowledge that and to have open conversations about the difficult times and letting your child know that they can do that. And encouraging them to be a part of the community if that’s something that they choose to do. And we acknowledge that there are lots of people who may choose not to for whatever reason, and often that can be a really positive reason where actually they don’t feel they need anything out of the community at this stage. But yeah, just encouraging them to really embrace who they are. There’s a really nice saying that I resonate with which is: *having a cleft has made me into the perfectly imperfect person that I am, and I like who I am.* And that’s something that I think every parent can help to foster in their child by an environment of love and acceptance and support.

Kate - Great thank you. So Rebecca, I hope that answers your question. We’ve got a few more. A question from Jennifer: “I’m curious if there is any data on the rate of drug and substance abuse among cleft affected people? I wonder how high self-medicating is?”

Kenny - That’s a really good question, Jennifer, and it is something that we asked in the survey. What we found wasn’t anything that would indicate particular concern over and above the population averages. So that’s why we’ve not really gone into it much here. But to acknowledge the point that we did find, when we were talking before about some of the positive things that some people did to manage difficult days, there were behaviours in there including self-medicating that we would identify as areas of concern for a very small proportion of people. Again, a proportion that we felt was in line with the general population, and usually when looking a little bit closer this was also symbolic of other things that may have been happening in their life, where it didn’t seem to be necessarily just cleft that was a contributing factor there. But it’s definitely something that can happen, and it’s worth being aware of. But the data that we found was not indicating that it’s a particularly prevalent issue in the cleft population, but great question.

Kate - Yeah, thanks Jennifer for bringing that up. The next one is from Gayle: “I’m very conscious of the way my voice sounds. To me my voice sounds normal, but to others it sounds like I’m talking through my nose, and I sometimes notice it when I’m saying certain words and when I can hear it I hate it and I get embarrassed by it.”

Kenny - Yeah, I mean that’s a really tricky one Gayle. And I think just to pick up on that, I think a lot of people can identify with that, and we saw that come quite strongly through the survey. I mean, in terms of the support that’s available, if you were to want to do something about that then as we’ve mentioned, you do have access to the cleft team. Within that there’s obviously the psychological care which might help some of the self-thought around how you’re feeling. But also, you’ve got the option of having an assessment for potential speech therapy or potentially for further surgical care around speech concern, if you feel it’s that much of an issue for you. So I mean there are options available.

That doesn’t downplay how you’re feeling, though, and we are all our own toughest critics, which is hard. And it’s particularly hard when we do perceive that other people pick up on something. Whether or not they choose to be kind about it, it still is a thing in our own mind. And so if it’s bothering you to that extent where you’re using phrases such as “I hate it”, I’d strongly encourage you to consider returning to the cleft team and having a chat with the team there and just seeing what options are available to you. Either in terms of that psychological support around managing those feelings, or anything that might be able to address the underlying concern that you’ve got with your speech. So thankyou Gayle for reaching out, because I’m sure a lot of people will have heard what you’ve just said and thought, “yeah me too, I know how it feels.”

Kate - Yeah, and it looks like from the comments that there are lots of people thinking and feeling the same thing, so thanks for bringing that up Gayle. So another question from Sharon, she says, “why is it I don’t like looking at other people with cleft lips? I feel really uncomfortable and it bothers me that I feel like this.”

Kenny - Yeah, again a really good question, and not one that I can answer specific to your circumstance, because without knowing you and all the things that have happened in your life, and I’m not a psychologist as well it’s important to point out, but what we have seen is that a number of people have told us over the years that being part of the cleft community isn’t necessarily something that they want to identify with. It sounds like there may be some element of that happening with you. I mean, obviously you’re engaged with the community to the point that your listening to this and engaged with us in that way, but it may feel quite uncomfortable or confronting perhaps for you to engage with other people who were born with a cleft. It may bring up some emotions or feelings of your own. And again, I would suggest if it’s something that is of concern to you and your feeling that really quite strongly, it may be something to unpack with a psychologist.

But I don’t think it’s inherently unusual. I think you’ll find there’s a group of people out there in the wider cleft population who very much would feel the same way and they’re obviously the people we don’t often see engaged with CLAPA in quite the same way. They’re less likely to come along to events, and I think there’s definitely a proportion of people who will feel that. And I don’t think its inherently wrong to feel that way. People deal with things in different ways good on you for acknowledging it as well, I’d say, because it takes a level of maturity to recognise that in yourself. But if it’s something that you’d like to see change for you, then definitely it may be something that you start by reaching out either to the psychologist or our peer support service where you can talk to someone on the phone and it’s a slightly different stepping stone to engage with.

Kate - Yeah, and to add on to what you said. We actually had a reply to Sharon’s comment from Jennifer saying, “I wonder if it’s a visual reminder of your own cleft. Its more or less easy not to see ours and we can in some way forget it, but seeing another person with a cleft is a, so to speak, in your face reminder.” So that really echoes what you’ve just said.

Kenny - Yeah I completely agree with Jennifer there. I think it will force you again to relive, perhaps, something that you’ve gone through and it’ll bring it to the front of your mind again. If you’re just going about your day and then it’s brought it back and all the emotions attached to that… So I can see that.

Kate - Yeah definitely. Jennifer actually also added, “I think allowing ourselves to be vulnerable can be tough considering how often we have been vulnerable with our choice.”

Kenny - Yeah, a really excellent point as well. It isn’t easy to open up about those things either, and often, as you say, that choice is taken away from you. So then if you do have it you might be more reluctant to use it.

Kate - Yeah absolutely. So another question from Jadie, so thanks for asking. She says, “is it OK to be anxious about my little girl with a bilateral cleft lip and palate starting school? I hear so many horror stories from people about being bullied, about how she looks and sounds, and I feel quite helpless.”

Kenny - I think it’s a completely normal reaction to feel anxious and concerned about what your child may go through, and the journey that’s ahead from them, because it is uncertain. We can offer some reassurance about certain things, but reality is that in individual situations, we don’t know how they’re going to play out until they do. What we do know is that for all the reasons we were mentioning before, society is becoming a more accepting, more positive place, where we actually value the diversity in people rather than seeing it as something to be feared or concerned about. But of course you just want the absolute best for your child as everybody does. And at home, you’ve got a lot more control about that, and then when somebody goes to school that’s taken out of your hands. So I can totally understand the feelings of anxiety.

Again, I’m probably starting to sound like a stuck record here, I would recommend chatting that through with the cleft team psychologist. They’re there for you as well, to get some strategies. But also talk to your child’s teacher about the concerns you have at that point. Ask them how they are going to include your child in the class, and help them establish those friendships and things. Because what we know about the early years in school is that it’s as much about getting a good social grounding as it is about getting an academic grounding. So yeah, like I said to the first question, just acknowledging for your child that you’re always there to have those conversations with them when those difficult moments come up. And as I’m sure any parent of any child will tell you, difficult moments will come up in a child’s life, and just letting them know that you’re there and you’re happy to have those conversations and be a sounding board. I think that’s really, really important. So yeah, I hope that answers your question a little bit, but yeah I would talk to the psychologist, talk to your school teacher, and keep talking to your child as well.

Kate - Thank you Kenny. And thanks for asking Jadie. So I think we’ll have to wrap it up now as it’s been over an hour now. Thank you so much to everyone who tuned in, this has been the first of its kind for CLAPA live, and we’ve really enjoyed doing it and reaching out to you in this way. So as well, we can see that some of you may have been engaging with CLAPA for the first time tonight, so thank you so much for getting involved. Thank you if you’re taking part in awareness week, it’s great to see you tagging us in your posts and sharing your stories and everything. It really is amazing so thank you for that. And if you’ve enjoyed this live stream we can definitely experiment again with more videos to see how that goes. So yeah, thank you so much for coming along, it’s been great. And as Kenny has sort of mentioned throughout this whole discussion, cleft talk the podcast is part of the adult services project, they have devolved into a lot of these topics that we’ve covered in a lot more detail. So it’s definitely worth checking out on our website, and we’ll make sure to link it in the chat again for you. And of course, if you are wanting to get involved with awareness week this week, we’ve got lots of ideas on our website to get involved, and that’s CLAPA.com/AW20 so definitely get involved and thanks so much for coming along.

Kenny - Thanks again to you all for your questions and for engaging with us. It’s been our pleasure.

Kate - Thank you very much, and we’ll see you again soon.

**With special thanks to CLAPA Volunteer, Ruairidh, who transcribed this Q & A. If you have any questions about this recording or research paper, please contact** **adults@clapa.com****.**