



LEEDS MENTAL HEALTH CRISIS SERVICES 2018

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Introduction

Battle Scars is a small Leeds-based charity focusing on providing support to anybody affected by self-harm: those who self-harm (from cutting, to eating disorders, to self-neglect - any method apart from drugs and alcohol) and those who are supporting them (family, friends and professionals).

A very large number of our service users have experienced mental health crises. This is often mentioned at the peer support groups (Leeds) as well as the Facebook group (worldwide). As a survivor led and run organisation all the members of the board as well as the founder and CEO have been affected by self-harm but also have had personal experiences of mental health crisis.

Out of all the people mentioned above a large percentage have reached out for help by ringing the Crisis Team or attending A&E¹ to see the Acute Liaison Psychiatric Service (ALPS). Unfortunately quite often discussions surrounding these interactions are rather negative. Following further involvement of the charity with the above mentioned as well as other NHS services it became apparent that feedback is much sought after and difficult to obtain. Battle Scars offered to gather such feedback as a non-NHS third party.

We held 9 focus groups, one 1-2-1 session and one telephone consultation. For a period of approximately 2 months we ran an on-line survey for those either unable to attend any of the groups or preferring total anonymity. We took all precautions to avoid duplication by clearly asking participants to do one or the other (in-person or on-line) and we had 41 participants. The groups, 1-2-1's and surveys were open to all adults in Leeds who had experienced mental health crisis, had supported a loved one through it or, in cases of professionals, referred a patient/service user to the crisis services. They did not need to be Battle Scars service users to participate.

Due to the different ways Crisis and ALPS operate and are accessed, a number of questions asked were specific to each service while others applied to both.

The decision was made to almost exclusively use quotes in this report and allow the readers to draw their own conclusions. A summary of suggestions is available at the end of this report.

¹ In this report we will refer to the Emergency Department (ED) as A&E. Within Battle Scars ED is commonly used as an abbreviation for Eating Disorders and this could result in confusion.

Stable or in crisis

What do you consider a stable state?

The answers varied from “when I’m happy and content” to “when I’m not self-harming and I can push the suicidal ideation out of my mind”.

The most common answer given was linked to being able to function, even to a basic level: “I can get out of bed”, “I can brush my teeth”, “I can do things without being annoyed by them”, “I can go to work”, “I can look after my child, that’s the best I can get”.

A few people mentioned being ‘calm’ as their stable state.

People with bi-polar described their stable state as “when I’m balanced, not depressed or high” and “when I’m not manic”.

For some being stable involved being able to enjoy things and even remembering the events of the previous days. For others the effectiveness of their support was an indicator “when a person feels able to manage their symptoms and risk to self or others with usual or reasonable levels of support”.

Self-harm and suicidal thoughts played a large part in whether one felt stable or not. Quite often it was not their absence but their intensity that indicated whether they were stable or not “when the self-harm thoughts’ frequency is low” or “when I am able to keep myself safe”.

While dips and mental health difficulties were accepted as part of life, being able to do simple tasks and “do something constructive” was very important for almost everybody who participated.

What do you consider a mental health crisis?

It appeared that answering this question was easier than answering what was considered a stable state.

Thinking of suicide and planning suicide were the criteria for most of the participants: “feeling suicidal and acting on it”, “when I’m Googling to get the details of the plan decided”, “when I feel I’m losing the ability to pull myself back”, “when I can’t keep myself safe”. Or when the person is a danger to themselves and others because “a person feels unable to manage their symptoms”.

Other comments included “thoughts of suicide don’t mean crisis. It’s intention. It’s planning it” and “when I’ve planned it down to the last thing. When I have said my goodbyes”.

Nobody considered low intensity self-harm thoughts (not intrusive enough to distract from other tasks) as a crisis. Instead “thoughts of self-harm and suicide are constant and intrusive” and “thoughts are too frequent” were more of an indicator. One participant commented “when I’ve gone beyond the point of rational thinking. Severe self-harm because obviously not all self-harm is crisis. Sometimes self-harm is to stop crisis”. Another defined their crisis as “the suicidal thoughts. Probably should be self-harm but my idea of a mental health crisis is when I’m actively planning suicide”.

Other descriptions of mental health crisis included “when life is unbearable”, “when I feel worthless”, “when I don’t care (if I’m caught self-harming)”, “when I get in a negative cycle, get psychotic”.

Even though every person’s mental health crisis is individual to them, there were, of course, many common characteristics like the fact that for most people a crisis builds up over many hours, days or even weeks, sometimes to the point where they push others away (with or without violence) or are unresponsive.

For some a crisis was due to clear external triggers "most of the times I've hit crisis point they were due to reactions to situations".

Those living with bi-polar stated they're more likely to need crisis intervention during the manic episodes than the low "I wouldn't know I'm approaching crisis... and I wouldn't reach out... I won't do anything to stop myself carrying out the dangerous ideas. I'm not thinking of suicide. If I kill myself it will be accidental".

A comment many related to was "each crisis seems to be worse than the last one. I'd think I've reached that crisis point because I'd start having suicidal thoughts but the next time it's because I'm planning it. Often when we don't get help early on, things just keep escalating. We don't 'reset'. The gap between not being in crisis and being in crisis becomes smaller and smaller".

In certain cases it was felt that mental health services play a big part in escalating the situation to crisis point: "there seems to be a hierarchy of conditions. I'd be taken more seriously if I said I'm depressed than I'm having a panic attack. When I have a panic attack I think that the world is ending right this second. If I said I'm about to attempt suicide it gets taken more seriously than I feel suicidal. It's as if they're pushing you to get to the more serious point instead of catching it a bit earlier"; "I come up with some horrendously dangerous ideas to force them to give me some help".

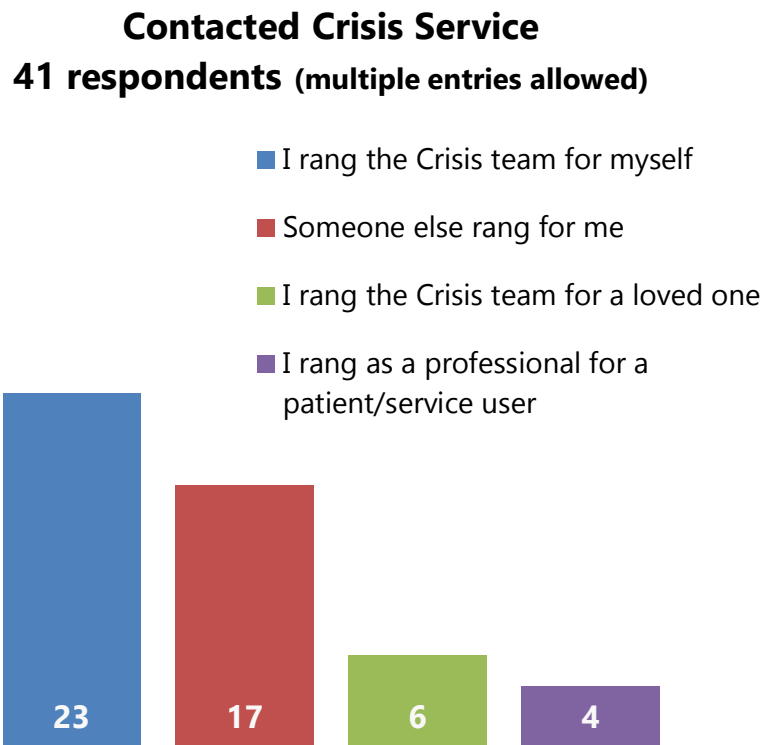
Receiving ongoing support is unfortunately not a safe method to assume someone will not experience mental health crisis: "just because I'm receiving counselling doesn't mean that in the days in between I will not reach crisis point".

It was recognised that awareness comes with time and by being able to talk about it "awareness to recognise what my early signs are and having discovered ways to stop myself heading down that path"; "I might need help to become aware of my early symptoms".

Crisis Service

How was contact made?

Contact with the Crisis team is made by phone but it's not always the person in crisis who makes the call. In order to get a better picture of how this contact was made we offered the choices below to the participants:



"My GP arranged for the crisis team to contact me when I was struggling. They couldn't contact me the same day due to high demand so my GP rang me to let me know they would be in touch the following day. I spoke to a lovely nurse for about an hour and she helped settle my mind, she heard me out and did her best to ground me. I was very pleased with the service I was given as making phone calls is incredibly difficult for me".

At which point do you decide to call the Crisis team?

In some of the responses the point they would call the Crisis team matched their point of crisis: "when I can't see a way out", "when I realise I'm unable to keep myself safe", "when I feel suicide is my only option", "when I have nothing left to hold me back".

In the view of a professional "(when) I feel a person cannot keep themselves or others safe with their current level of support in place from family, CMHT, ICS. Or if I cannot contact someone I believe to be at risk e.g. if they go missing".

Quite often the person recognises that they do not wish to go ahead with their suicide plan "when the small part of me that wants to live makes that decision". Other times this appears to happen subconsciously. For the majority ringing Crisis is not their first action, they do not ring unless

the suicidal thoughts/planning have been present for days or weeks and they feel the situation is seriously deteriorating or despite having “tried everything they’re going to suggest to me... and things are still getting worse”.

A few people admitted that using the phone was not an option for them. They would prefer a texting or email service.

While most will only ring at the last moment “if I catch it right, just before the point of overdosing”, it was acknowledged that making contact with the service before the “tipping point” would be more beneficial: “I have to ring before the full crisis hits. Because after that I won’t ring. I can’t think. But we’re not supposed to do that. Six hours later I ring an ambulance”. Also “because otherwise it takes so much longer to get over it”.

In a number of cases the person in crisis refuses to make the call and has to rely on another to do it: “my partner usually insists we do something. I don’t want to ring them”, “my partner had to do it, I wouldn’t”, “I refuse to do it after too many bad experiences where they made me worse. My GP or my husband has to ring them for me”. On more than one occasion the person’s GP had to ring.

There were many negative responses such as “(I call the Crisis team when) I have no other option. It’s never a good experience. I’m never treated with respect and they rush me off the phone”, “when I don’t know what else to do. But I’m never ringing them again”, “I haven’t rang them for a while. You just get ... ‘go for a walk, have a bath’. So I don’t even think about ringing them now”, “I’ve given up ringing them”, “I wouldn’t because of my past experiences”. Or simply “I don’t” or “never again!!!”²

There were cases when participants were able to recognise their early warning signs and take action “I am able to recognise when I get psychotic and I know what steps to take”. Even though a call to the Crisis services could be required “sometimes it comes on so rapidly”.

It was also mentioned that “it can vary because of where the ‘starting point’ was”.

What do you expect when you call the Crisis team?

A few predictable answers were received such as expecting support, advice on ways to manage, “to be helped through a difficult experience”, to be helped to calm down even if “the person gets so aggravated and starts shouting not to hang up on them”, “to help distract me”.

Being listened to, given the space and time to speak were some of the issues raised “I expect someone to listen”, “somebody to take the time to hear me out”, “to speak without being rushed”, “not (to be) fobbed off”, “that they want to listen, not like they’ve been forced to be there”; “felt like there was no compassion, not taken seriously, felt like they thought I was putting it on and I was not really that bad”; “a sympathetic ear. I get the impression they don’t want to listen to me. I get it, they’ve been doing it for hours but don’t do that job if you have had enough of listening”. One participant said “to feel like, even if they don’t do anything, that they’re listening. It comes across they’re waiting for you to get through your babble so they can tell you what they have to say. I want them to take it in, to acknowledge what I’m saying, not just to say their bit”. One angry survey entry was “someone to actually know what the **** they are talking about or have an ounce of compassion or maybe even to be treated like a human being”. A request was made to “be patient. As soon as I pick up that you’re no longer patient with me I’ll hang up. Have a conversation with me”.

Other expectations included compassion, “to care”, “a bit more sympathy: ‘we’re busy, we’re really sorry’. That human touch”; better knowledge about the impact of mental health issues,

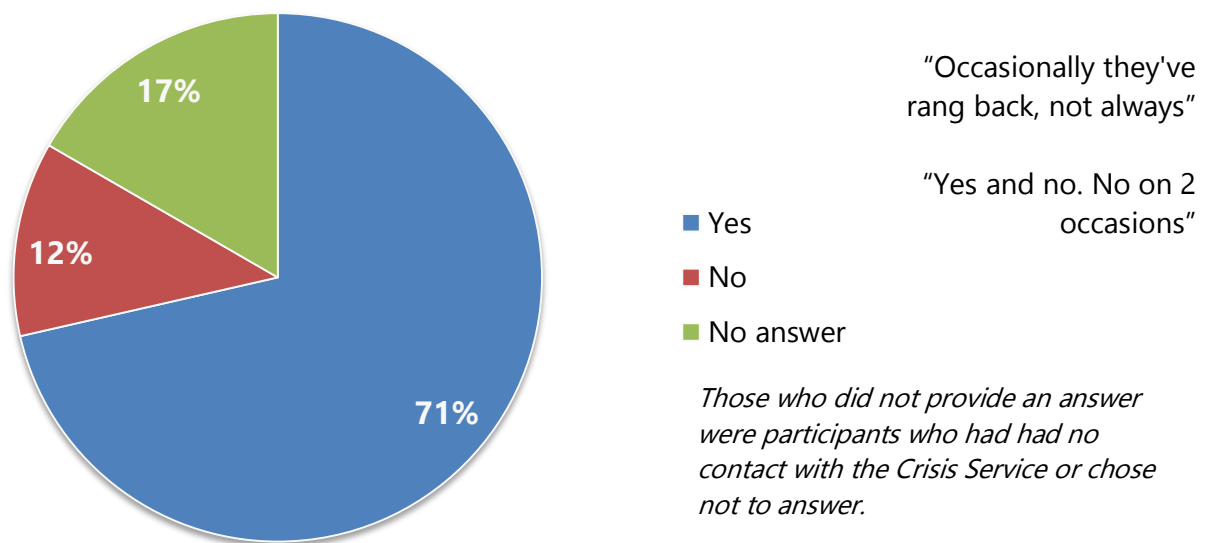
² As written on the survey

empathy, courtesy and honesty: "I've been lied to before and later found out what I was told was not the case. And I was told that they won't assess you if you're under the influence of alcohol or hung over. If you're drinking to cope there is still a cause. Nobody drinks and then rings the Crisis team for a laugh. They're using these techniques to pass you on or get rid of you"; "I called the crisis team when suicidal in Nov 2012. Was told the crisis team is for 'emergencies only'. This was a factor in my first suicide attempt 3 months later after giving up on any chance of help".

Another participant added the autistic person's perspective "if you psyche yourself up to ring you can tell you're not getting a human response. Especially as autistic people are way too sensitive and will pick that up and won't do it again. Genuine responses are a must".

We asked participants to indicate whether they were called back by the Crisis team following their initial contact by selecting yes or no on the form everybody filled in. The yes or no option did not provide the clear image we were hoping for despite appearances. It was commented a few times that they have selected yes even though there were occasions when they did not receive the call-back. It was impossible to record the response for every single time they had made contact with the service.

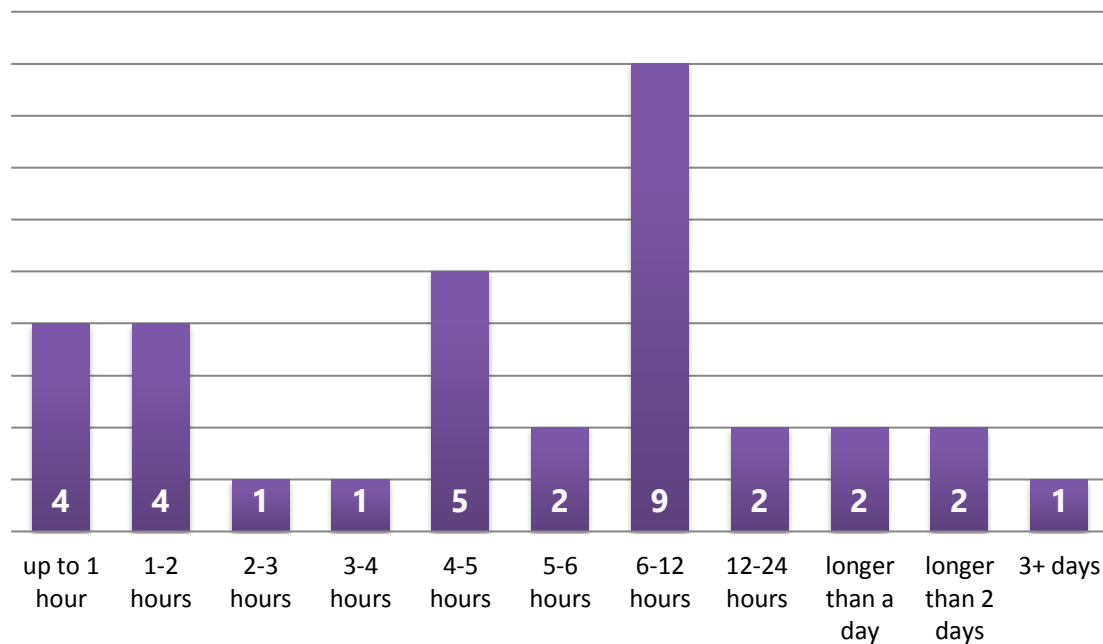
Did Crisis ring you back? Total entries: 42 (multiple entries allowed)



The call-back time varied a lot but most commonly it took between six and twelve hours. There were a number of comments linked to the time of the call-back ranging from "to be rang back within a reasonable time", "to speak to someone quickly, maximum an hour" and "getting a call back within 72 hours is way too long. Half an hour is too long", to complaints about not getting called back "ring me back. Get more staff!"

It was important "to have an honest response about the call-back. If I have to wait for 6 hours I might as well go to A&E. I will have seen someone within those 6 hours. Crisis may ring back and still tell me they're too busy to do anything so I wasted all that time and then I have to wait even longer at A&E with my mental state constantly deteriorating".

Length of time the Crisis team took to ring back Total responses: 33 (multiple entries were allowed)



Clearer and realistic expectations were mentioned: “be honest. Telling me ‘we’re busy’ means different things to different people. Do I have to wait hours or days? To be given a more definite time scale, a clearer image of how busy they are”, “no promises. Not to be told ‘someone will ring you in an hour’ when it’ll be more like 3”, “tell me are you 2 hours busy or 6 hours busy? The carers need to know too”, “a phone call back the same night and indicator of when the call will be – but we never get this”. A participant commented that even if no call-back would be possible on the same day they would rather know: “tell me if nobody can ring me today. I’d rather be upset at that point than find out later when things have got even worse. It feels like a slap in the face”.

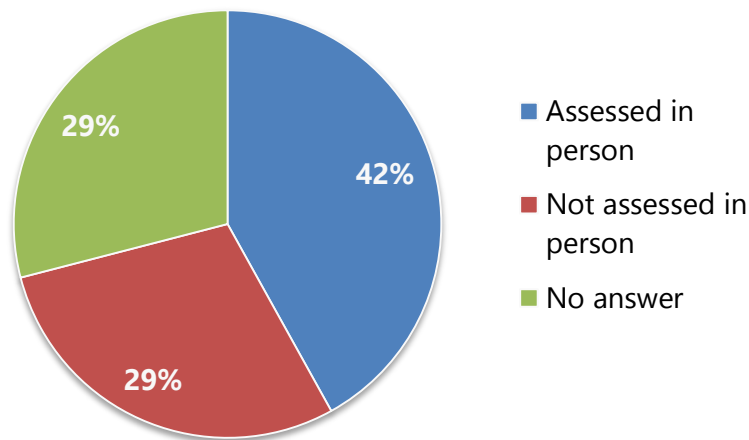
There appears to be different responses depending on who is making the call “if I or my GP rings to get a call back”, “to get the same response when I ring or when my partner rings or when my GP rings”; “to get the same treatment if I or a professional rings. Sometimes the professionals ring because they have a duty to act even if I’m not in a full crisis yet. If my husband rang them and then they spoke to me they could ask me if I was happy with my husband ringing them. If I said no, they could follow up with ‘why not?’ My reply would be ‘because I don’t want to be stopped’. That could give them a good indication what state I’m in. That is more serious than my GP ringing after I told her I had thoughts of suicide”.

“I want to be taken seriously. I want to be believed like my GP gets believed when she rings for me. Crisis tend to ring back or stick to the timescale much more closely if a professional rings them than if I or my partner does. I expect them to respond to my calls like they responded when my counsellor rang. She was told I’d be called back within the hour and I was. I spoke to one of the psychiatrists from the Becklin Centre. And the assessment team came out the next morning. Now that is what I expect from the Crisis team”.

There are cases when it obviously makes no difference who rings: “last time my GP insisted we rang Crisis. She rang. They rang me back 3 days later”.

Some of the participants had the phone call followed up by an assessment but once again it was mentioned that they might have rang numerous times but only assessed once. Therefore the ‘yes’ option was selected.

In-person assessments by Crisis



“When I was manic, they came out to me when the GP rang. When I called for myself they didn't come out. When I called for my partner they refused to help because she lives out of area, even though she was staying with me in Leeds.”

Other comments about the in-person assessments were about taking place during the night: “(I expect) to be assessed during the night time, not because the police were called out” and there was a lot of frustration about the lack of assessments in general, “not to have to ring 4, 5 times to get an assessment. Delays upon delays”, as well as follow ups. A professional commented “(I expect) advice to manage crisis situations. I have come to expect they won't be able to visit a person if there is any other way they can get help, but it would be nice if they could be relied on to visit a person more regularly”.

A number of participants felt that too many assumptions were being made “do not assume that just because I've got my partner around that I won't get out and try to kill myself. Or that because I didn't try it before that I won't try it this time”. Previous history is not perceived as a safe way to gauge current intentions. Further assumptions about who someone is with relating to the relationship between these people were brought up: “if I live with my mum and dad, they shouldn't tell me that just because they're around that I should be fine. I don't have a good relationship with them and I do not consider them part of my support network. If anything, they often contribute to the crisis building up. Or have caused it”.

“We are people, not just a voice at the other end of the phone. I know it's unlikely I'll tell them exactly what is happening, like the razor in my hand. And if I tell them I want them to listen. Not dismiss it because I've told them about it and assume I am not at risk”. The level of risk sometimes increased due to the response: “When I'm going towards the bridge and I realise what I'm doing and I ring them asking for help being told 'obviously you rang us so you're not going to do it' is making assumptions that are dangerous. At that point it's a challenge, it's like they're daring me to do it”. “Not to be told to have a bath. I have scalding hot baths as a form of self-harm. Being told to have a bath may encourage me to do exactly that”.

Certain suggestions were felt to be completely inappropriate, even infuriating, such as have a hot bath, go for a walk, read a book, have a cup of tea - “it's so scripted it doesn't feel like they're linking anything to what you've told them. The 'cup of tea', 'have a bath', 'go for a walk' is a red rag to a bull”, “and don't suggest that rubbish about having a bath!” – even ring a friend can be an unhelpful suggestion “because I've managed to talk to my friends all day which helped me keep things at bay and once they've gone to bed I can no longer control my thoughts, ringing Crisis and be told 'you have a lot of friends, talk to them' which is a bit tricky at 3 am, is not the help I need”. “Many people won't feel safe to go out. They may have been indoors for days, weeks. Or they may

be paranoid and they don't trust anyone, they don't trust themselves". "Not to give advice like 'try lying down and close your eyes and see if you can sleep'. As if I haven't tried that". Being told to ring the police or go to A&E was considered unhelpful, even confusing advice.

Being asked about intentions was something that was expected by many: "to be asked if I have a plan", "if asked a direct question I could give them a direct answer and tell them I was about to overdose". Even though in one case "being asked what my plan is certainly has its uses. But after I said what it was in detail she asked 'will that do it?' I was Googling it to find if the number of pills I had would do it! Maybe I should test it out and see what happens".

There were many comments about the questions being asked, some referring to the questions being too closed while others saying the questions needed to be more specific: "not to have to go into my whole life story. Focus on what's troubling me there and then", "to be asked 'what is bothering you the most right now'", "maybe being asked 'when was the last time you enjoyed something?'"

While the difficulties of obtaining the full picture when speaking to someone on the phone were acknowledged, many participants believed that with the correct questions such a picture would be easier to obtain: "not to be asked the same questions 'are you eating, are you sleeping, how is (your) concentration'. It makes me angry. Over the phone – they don't come out to assess you – they can't see you with a floor full of tablets", "they can't see my anxiety... just because I am able to express myself that's not enough. I was asked if I'm drinking, eating or checking if I'm drinking alcohol. Just because I am doing that doesn't mean I'm not putting a noose around my neck". "Yes or no questions don't allow me to say what I want to say. Maybe being asked 'is there anything else you want to tell me?' could make me think. If I say I'm suicidal, alarm bells should be going off". "With yes and no questions once I've answered I'm considered capable and there is no help coming. Maybe asked to elaborate would be helpful". "(I expect) to acknowledge that even though part of me wants to live and that's the part that has made me reach out to them, there is also a huge part of me that wants to die. That's why I'm in crisis. This internal battle is going on and I need help. If they don't ask me the right questions they'll never know about that. Or they don't ask the right way. In that state, I cannot often speak very well. I know it's harder for them but the right questions can make a big difference. If asked questions that show this person cares, I can start opening up. Otherwise I'll just say yes or no and they won't get half the picture". "It sounds like they're reading the same questions on the computer". "The Crisis Cafe asks 'if we couldn't offer you a place tonight, what would you do instead?' That is a really good question because you can find out if they have a plan, they might offer it. Maybe the questions are too closed and they don't allow you to express what is going on".

"More questions such as 'do you feel that if you managed to get through the night you might be able to face things better tomorrow' would give the message that I need something very short term. Tomorrow I could ring my CPN; I could reach out to my friends or to the Battle Scars group. It could make me think it through a little bit and help me put a plan together".

"The worst question to be asked is why. Because there is no simple resolution to that question... The reasons they are hoping for are issues with work or relationships and they seem unwilling to look deeper".

"They need to acknowledge that my reality can be very different to theirs in that situation. Often they try to reassure but it makes things a lot worse. You can't tell me that my reality is a lie".

"Ringing the Crisis team is basically like playing the lottery. The response you get very much depends on who you get through to".

For the majority of participants ringing the Crisis team was a last resort action. One that requires a lot of effort and courage as often they are acting against their thoughts.

Other expectations included “not to feel like they’re ticking boxes to cover their backs”, “not to be made to feel that those who are supposed to help do not want to help” or “to feel they want to help but can’t. Not to make me feel like a nuisance. To feel they do care”; “not to be judged based on my BPD³ diagnosis” and “given accurate information about other services. Being told to just Google what is available in my area is not helpful”. Also having clear criteria was frequently brought up “have clear criteria that don’t shift and change all the time. If the criteria for a crisis is that I’m a danger to myself (self-harm or suicide) then when I ring because I’m a danger to myself it should be acknowledged that I’m in crisis and I need their help” while “those who ‘play the system’ are very few. Even if they do, something is really wrong here. What are they getting out of this ‘attention?’”

Being asked ‘what do you want from us’ was an issue with many: “what am I supposed to say to that?”, “I need you to tell me what you can do”, “have you just asked me 20 questions to then ask me that?” while some participants felt that they were made to feel more guilty “if I have family around or similar and they tick that box it feels like they’re putting all the responsibility on these people. That would make me feel much more guilty”. There is further impact “the crisis affects the whole family. There is only so much a carer can do before the professionals need to step up. Someone with some tools to help everybody through it”; “as a carer it’s like you’re being asked ‘what is the extra difficulty that you can’t deal with it?’ as if it’s our fault”.

Suggestions of a texting option were mentioned especially by people who are autistic or who have severe anxiety making phone calls. Also, a video option as a better means of obtaining the fuller picture “so the staff can see what state we’re in and what environment we’re in”.

There was often a feeling of resignation in the focus groups when asked what they expected from the Crisis Service and as one participant put it “not much quite honestly”.

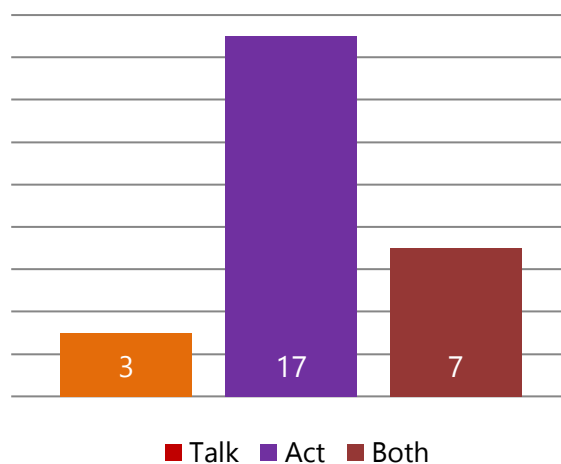
When you ring the Crisis team do you need someone to talk to or act?

Talk or act?
Total responses: 27

“It varies. Sometimes talking is enough. Other times I need more when I’m not feeling safe.”

“By that point I’m past talking to people. I’ve exhausted all that.”

“I need someone to act. I wouldn’t choose the Crisis team as someone to talk to.”



There was a clear majority of expectation for the Crisis team to act upon contact. Those who chose both often clarified: “it depends on what point I rang them at. If I’ve been called back pretty quickly and they’ve spoken to me, I’ve managed to calm down. If I’ve gone past that point I need to be taken out of the situation, away from home”; “at times I feel I have needed both someone to talk to and someone to act. The Crisis team have not been helpful when I have rung them in a crisis”; “I

³ Borderline Personality Disorder

need someone to listen and understand. But I need them to take action as a result. To be told after a minute or two 'ring back tomorrow' feels dismissive and that no one cares and there is no hope. If it had got bad enough for me to call I expect something to happen"; "If I'm in a talking mood then talking can help. If I'm too wound up and anxious I want action, someone to come and see me and have an in-depth assessment. Each presentation is different and should be treated separately not basing what they do on how you've been before. Just because someone rings them when suicidal but haven't killed themselves yet means nothing".

"As a professional I am calling the crisis team for urgent advice or for their help to see someone or contact someone for support. I know a lot of people find it helpful to call to talk but I think by the time most people are calling Crisis they need immediate help and someone to act, and find it very difficult when this is not offered".

Another participant, without elaborating on what they needed and what they received, described their experience as "excellent. They acted and helped me through a very difficult period".

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On a separate occasion during one of the Battle Scars peer support groups the question "who has made contact with the Crisis team?" was posed. Nine out of twelve members raised their hands. A further question was asked: "Who would ring them again?" No hands were raised.

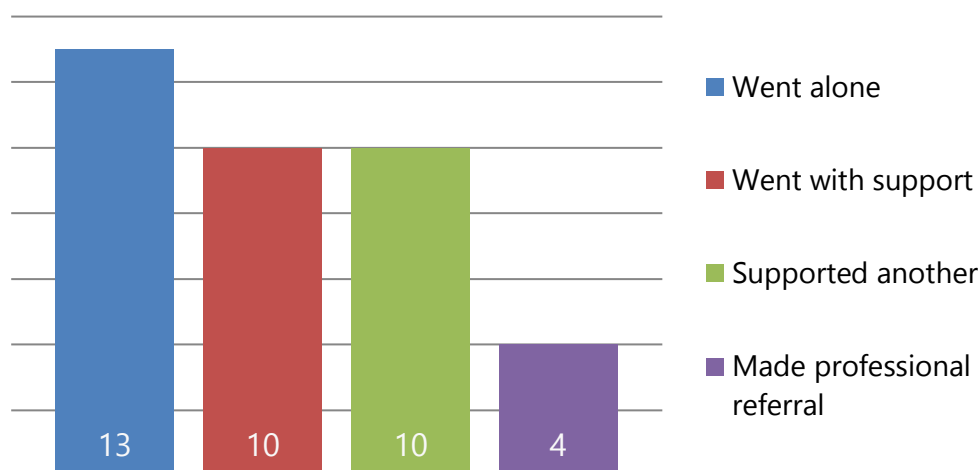
Acute Liaison Psychiatric Service – ALPS

There were a range of responses from the participants about their contact with ALPS as well as a few on line responses from professionals regarding referral to the service:

A&E presentations & referrals

Total responses: 37

(multiple entries were allowed)



At which point do you decide to go to A&E?

Most of the participants indicated that they would only attend A&E when requiring medical attention due to self-harm or following a suicide attempt. Also when at high risk of severe self-harm or attempting suicide.

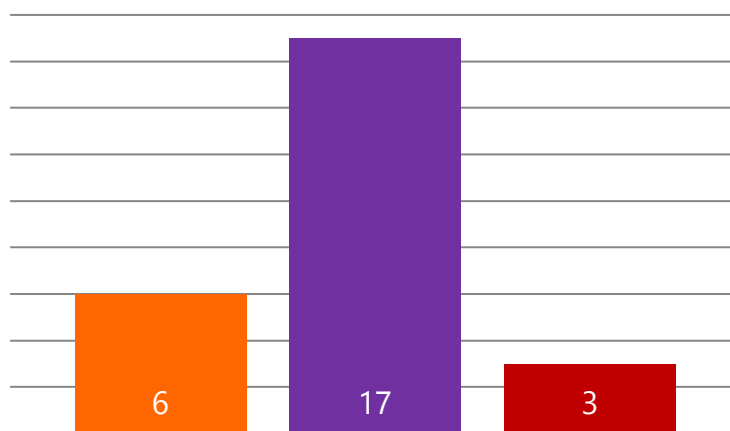
For some people attending A&E because of their mental health was not a choice:

Other methods of arriving at A&E

"After ringing 111 I was taken to A&E by ambulance."

"Never. I only go if forced to go by ambulance / police. It's not the right place for someone so distressed and staff treat you really badly."

"Only when I'm taken by the police under section."



■ Taken by police ■ Taken by ambulance
■ Taken under section

Sometimes it's considered a quicker way to see someone and get an assessment compared to ringing the Crisis Service. A professional commented "(I refer to A&E) when a person has already harmed themselves, or I feel unable to leave the person for Crisis to see later, or if I feel they need immediate medical attention".

All participants who had presented to A&E due to their mental health stated it would be a last resort "when I'm about to act on my suicide plan", "when it's a choice between killing myself and going there. I wouldn't go before it's reached that stage".

Some who have attended before stated they would not attend again "what is the point of going and sitting there for hours to be sent home?", "never again!!!"; while others simply wouldn't: "I'm worried they'd take my control away from me", "I've heard horrendous stories about A&E", "it wouldn't even enter my mind", "I'm too scared to go. I don't want to be a nuisance and made to feel worse. I'm worried about being sectioned or what will happen to my child", "even in a stable state it's too noisy"; or were not aware it was an option "I hadn't thought about it. Is there a special room at the side for people with a mental health crisis?"

What do you expect when you attend A&E and see ALPS?

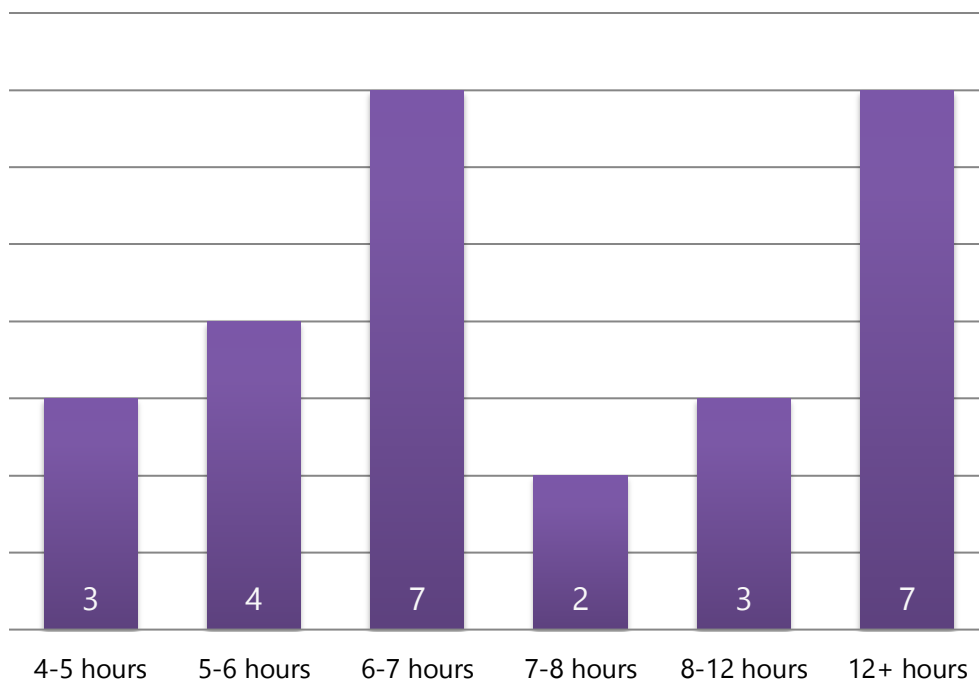
The time scales were one of the first things mentioned. Participants were asked to state how long before ALPS came to see them. We specified that it had to be following a presentation to A&E and we are aware that some of these assessments were carried out at A&E and that in some cases the visit took place on the medical wards following admittance.

Length of time to ALPS assessment

Total responses: 26

(multiple entries were allowed)

"I may have been waiting at A&E for 4 hours but this has been building up for days until I was crawling up the walls before I managed to reach out."



Expectations of actually being seen and of a quicker assessment were repeatedly expressed. The length of the wait was often combined with a lack of communication and interaction making the situation worse: "you get ignored... you feel no one cares"; "it feels like no one gives a damn. You have no reason to stay and not walk away"; "letting us know it's busy and how long it'll be before

we'll be seen. It was 4 hours before I was approached. During that waiting I was actually thinking of going home and taking more pills. They didn't think to ask me if I had more on me. Thankfully I had forgotten I had them"; "to be given more realistic expectations. I know the previous case can take longer than expected. But I need to be updated... to know I haven't been forgotten. If presenting to A&E with a physical injury or illness a nurse would pop in and check up on me. When I'm there with a mental health crisis I get completely ignored until ALPS come out"; "I understand the lack of money and capacity but while waiting it would help to be asked 'do you need a glass of water, how are you doing, do you need a blanket?' The staff were thinking more about the 4-hr stay at A&E than me. So at 4 hours they shifted me to another corridor"; "to be told if they're really busy and not to be told that I'm next... It was 12 hours later before they saw me. They said 'sorry, we were reading your notes'. What, for 12 hours?!"; "some people take the time scale they've been told literally. If that passes it seriously increases their anxiety"; "nobody keeps an eye on us, nobody checks up on us".

Perceptions and perspectives change while someone is experiencing a mental health crisis "time moves really slowly. 7 hours feels like 7 days. They don't appreciate how that feels... then they wonder why I've completely broken down after 7 hours".

A number of requests for a quiet room were made: "we get totally overloaded in the general A&E area"; "a quiet area to help me calm down. With staff checking up on me. Even if there are other people there who are also in crisis there is some camaraderie. We might even talk to each other" or to be shown to a cubicle.

There were cases where misinformation regarding the ALPS working hours was given "I've been told at 2 am that they don't work before 9 am"; in a separate case they were told 8 am.

Some participants queried whether the lengthy wait was intentional "do they take so long to come and see you hoping you'll get completely exhausted and go away?"; "it looks like ALPS stand back, wait until I'm OK to be sent home"; "(I expect) not to be considered fine just because after waiting for hours I'm so exhausted I want to go home and I don't want their help any more. That shouldn't be considered a result", neither should exhaustion be confused with de-escalation "it's the body that cannot take any more, especially after waiting for 6 or 7 hours. It will all be there tomorrow".

A few participants stated that they would like "to know who I'm dealing with, what their job is. As the patient I'm being put under the microscope but I don't know how you're going to approach the situation with me because the way a mental health nurse and a psychiatrist will deal with it are different"; "explain what they're there to do. A more in-depth introduction, nothing excessive but so I know if I'm seeing an OT I may still need to see a psychiatrist. Since they're assessing in pairs it would be very good to know who is dealing with me and what sort of skill sets they have between them. 'Hi, I'm ..., I'm going to help you in these ways' etc. Seeing a nurse after you've broken your leg will explain what they can do, the radiologist will explain what they'll do, also who else you need to see afterwards".

"ALPS will generally see people but this does not often lead to further support straight away" was a professional's view on the service.

The expectations of behaviour during assessment included being taken seriously, being believed and treated with respect, compassion and honesty were at the top of the list as well as "consistency with approach, rules, treatment, involvement, attitude. It can vary with the same person seen on different occasions, let alone different teams"; "proactive support", "emergency care" and "to be helped to feel better when I'm leaving than when I arrived". There were expectations of the staff looking "past the self-harm and see what is behind it", "to care and not be patronising", "no false smiles", "more understanding", "to validate how I feel" and "to have read my notes".

Many participants felt that their intentions were not queried, there was no opportunity to express how badly they felt and how much danger they perceived themselves to be in. "To be asked what my plans are and if I can keep myself safe"; "direct questions must be asked. If they don't ask they won't know. It's very hard to volunteer that information"; "to pick up on the heavy hints like 'I can't go on'". There were further issues after disclosure of suicidal intent: "not to assume that because I'm talking about killing myself and haven't done it before that I won't do it"; "if you're asking me what has stopped me killing myself before and I can tell you, build on it, don't just assume that it will simply do it again, it might not stop me this time"; "I'm scared of death but I was feeling suicidal. I was told that since I'm scared of death then obviously I'm not going to do it. That's not the point because I'm going to do it regardless of being scared of death at that point".

It was accepted as fact that certain responses to disclosed intent can seriously contribute to worsening the situation: "(I expect) not to be dismissed when I'm saying I'm feeling suicidal. I'll probably be back in a few hours after the police have picked me up from a bridge! I'd feel like I was pushed into acting on my thoughts to maybe get some help". Comments like 'if you want to kill yourself, we can't stop you' and 'it's not our job to stop you killing yourself' will have a very negative effect on the person in crisis. "I don't expect them to keep me alive but I expect them to help me do that. Ideas on how to calm down and achieve de-escalation".

It was felt that changes in attitude while making fewer assumptions is required: "not to be judged by whether I'm dressed or in my pyjamas. There are not an indicator unless you know the person well. I always get dressed, I don't even own pyjamas! So if you don't know me don't assume that just because I'm dressed I'm not in crisis. Also it might have taken me hours to get dressed. Or you don't know if I've been wearing the same clothes for days. If they ask if these clothes are normal for me or not they would get some idea how I am. If I'm not wearing shoes it's pretty safe to assume I'm not alright"; "being able to answer truthfully sometimes goes against you. It's seen as having an awareness and being capable".

The order of treating physical injuries before the assessment could take place was brought up: "the NICE⁴ guidelines say that there is no fixed order and assessments should take place before treatment of injuries if safe to do so", "focusing on the physical injuries when they're not life threatening or can wait until after the assessment and stopping the assessment to get them seen to, wastes time. Time management with ALPS seems to be non-existent".

In the case of admittance to the general wards, for example, following a suicide attempt, "to be seen earlier if on the wards. Once I'm past the danger point we should start planning for discharge and for community care. Being seen on the morning I'm due to go home is too late. They need to come out earlier so that the support is set up by the time I get discharged. Because of being seen last minute it took 5 weeks to get support when it could have been 3 if seen by ALPS much sooner". Also at that stage there might be an expectation that the person has had a chance to think things through "if my solution was suicide and it didn't work, chances I'll have another solution just because you ask me, is zero".

Some people would prefer being given a choice whether to see ALPS or not: "once I'm patched up or my bloods come back good, more often than not, I don't want to see ALPS, I want to go home".

Being asked 'what can we do for you?' can be counter-productive - "I want to know what the options are" - especially for someone who is attending A&E for the first time. While "if I know what I need, I want it taken into consideration not dismissed"; "once my concerns were listened to and action was taken. It made a huge difference to me and my family and de-escalation was achieved within a few days. The next time I reached crisis point a few months later I was asked what I find

⁴ The National Institute for Health and Care Excellence

helpful. My suggestions to follow the same approach were almost ridiculed. Why ask me if you're not going to listen to me? Once again, any hope I had was dashed. It took me 2 months to de-escalate at great cost to me and those around me".

Better involvement of family or loved ones could be helpful: "co-ordinating with family/friends after consent is given - if appropriate. Helps them to get the fuller picture. Being asked 'do you have any support? Would it be helpful for us to contact them?'; "consult with them, keep them in the loop".

Some inconsistencies were reported following shift changes "decision was made and then changed with staff change. Earlier intervention and following original plan of voluntary admission would have prevented a car accident and a section 2 days later. Even looking at the pure costs, this resulted in a 3-week stay in hospital".

Other expectations included "to be given the option to talk to them on my own if I want to say things I don't want my partner to hear because they are too traumatic", while "being suspicious about abuse is fine but I want to be believed when I insist that is not the case"; "to be asked about my mental state not to focus on the superficial cuts I have. To be asked what is at the top of my list, what I am struggling with the most"; "to get something there and then"; "to not get a leaflet"; "not to be told they cannot treat people like me".

The option to get a prescription "especially when looking for short-term help. Or get the A&E GP's to do it for them"; "to get medication if needed. Don't tell me I'm an overdose risk! I cannot overdose on one tablet! If I'm going to overdose that means I already have enough at home. I won't be just 1 short! 2 mg of Diazepam is not enough either. Maybe 5 mg. Or one Zopiclone".

"We should be seen by the same team, not separate Crisis and ALPS. Same treatment. ALPS can stay in the wards. I don't need a signposting service".

Even though in some cases it was obvious the correct procedure was followed by ALPS this appears to have been done without informing the person in crisis: "(I expect) to be told what they're going to do next. If they're going to ring social services and I'll have my child taken away, I need to be told that. I understand they may have to but it can't happen behind my back". "I was greeted by a very friendly mental health nurse who I felt genuinely cared and wanted the best for me. He went out of his way to get me information on different support groups and their contact details. However the following day I was contacted by social services and had my child taken from me due to a referral he had made to them. I understand he was doing his duty of care but he never told me he was obliged to contact them even when the child wasn't in my care. In the end he caused more harm than good and I completely lost trust in the service".

Some participants felt dismissed "if ALPS had done their job they could have treated me when I was suicidal. Instead they sent me home and sent the police around to do a 'welfare check' despite my PTSD and intense distress being directly related to police brutality which I was a victim of due to my poor mental health and receiving no treatment despite trying to for 10 years. As I would not let them in, they battered down my front door and dragged me away in handcuffs. This caused me to overdose and I was brought back to the same A&E I had just been released from. Only treated for physical symptoms, did not get to see a mental health specialist at all". "They seem to reinforce the mental health stigma by the way they treat us. By the way we're dismissed".

There appears to be different treatment on whether you live alone or not: "If you've got someone at home you're pretty stuck. You rarely get any help. And just because you're with someone doesn't mean that's helpful. It could be that someone is part of the problem. Even if they're not, they are not experienced or trained. I am fully aware I've had help in the past because I was alone. They cannot prioritise people who live alone. If there is family, if there are kids, they are at risk by you being at risk".

It was felt that a more holistic approach taking into account care already in place and physical issues is essential: “look at the full care I’m receiving and make recommendations”; “be aware of my physical difficulties and how they impact on my mental health. If I’m being asked what is causing me more trouble right now we could figure out that it’s my physical health that is the main trigger. Also to be able to see what medication I’m on”.

Some participants were given misleading information or advice: “being told to ring Dial House when they were shut wasn’t helpful”; “they should know which services are available when”; “I was told I shouldn’t talk to my GP about mental health because they don’t know much and it’s not fair on them. But who else is there?”

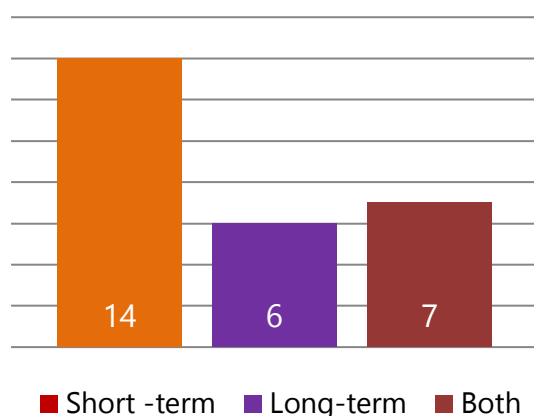
A final expectation expressed by many was “not to be passed around from Crisis to A&E and back”.

Are you looking for short-term or long-term assistance?

This is a question we felt had to be asked whether participants reached out to the Crisis Service or ALPS. The aim was to make them think what resolution they wanted from this contact and also to get a better idea of general expectations from these services.

Short-term, long-term or both?

Total responses: 27



"Immediate assistance to get through the crisis."

"I would love the right support to keep me stable and not end up in crisis. My crisis episodes are rare but I rarely find any help to get me through."

"Short term to help me overcome what is happening at that moment. But longer term someone who would listen, someone I can talk to."

The participants who stated they were looking for short-term assistance were aware that it was a matter of managing for a few hours or days: "it's usually an impulse. If I get through the next 5 or 6 hours then it's passed"; "something triggered it. I need something to get me over the next day or two to calm my thoughts down and start thinking again"; "to get me through to my next CMHT appointment, like a week"; "I need someone to stop me doing what I'm about to do"; "I need it now, I need something more than I've already had. I am past doing my other coping mechanisms. Once I'm past the crisis I don't want more involvement, feeling like I'm wasting it". Some were resigned to only being able to access short-term support: "I'm aware I need long-term which I'm not being offered".

"The Crisis team are there for crisis resolution. There are other services in Leeds for longer term support (IAPT, CMHT) but obviously accessing these services in the first place isn't always easy". Some saw their crisis as the effect of something more complicated: "I want them to treat the symptoms. I know treating the cause is a long process", as well as expressing the usefulness of short-term intervention "because otherwise it gets worse and then I need long-term assistance".

Those who stated they are looking for long-term help when reaching out to Crisis or ALPS during crisis commented: "the short-term NHS approach did not work enough for me", "the team are very quick to release you from their care / responsibility. I understand they are struggling with funding etc. but a little care can go a long way", "I've needed help for the past 12 years and never got it. There is no help for Borderline Personality Disorder because it's too stigmatised and the NHS and even mental health services are discriminatory towards PD's and issues like self-harm and suicidality".

Some of those looking for both were able to make the distinction between the kind of help they'd be looking for: "something to help me through that particular moment. It could be some Diazepam to get me through the night. But I'd also want them to contact my team and update them. It hasn't happened in the past. I need my CPN to contact me and check up on me but she can't do that if she doesn't know what's happened"; "it depends. Sometimes being asked the right

questions and talking is enough, so short-term. Sometimes, longer term, something in the form of a proper meds review”.

Other answers were a bit vaguer: “(I’m looking for) both but I don’t know what the long-term would be. I know I’d need something regular, more frequent than peer support groups. There are not enough alone. So, something to get me through the night and a follow up”.

How would you like to be treated?

Certain comments were repeated many times. The most common ones were “like a human being”, with respect (“for my personality beyond my mental health struggles”), dignity, care, compassion, empathy, honesty (“admitting they are trying to understand, not that they understand what I’m going through”), to be believed (“like what I’m experiencing is real”), to be listened to, to be taken seriously and to not be patronising: “I don’t want to be treated like an idiot. I’m hypersensitive when in crisis, I haven’t turned stupid. I can pick up every movement you make, that dismissive look on your face, that condescending smile. I can’t do anything about them but they are making me feel worse. I don’t need another kicking”; not to be treated like a “silly little child wasting everyone’s time”.

Participants expect not to be judged (“because of my diagnosis which happens a lot”), and to be dealt with quickly, sensitively and professionally. “I want them to be friendly, not condescending though, then I find them rude”; “(I’d like to be treated) like other patients with medical issues are treated”.

Some comments were made specifically about ringing the Crisis team: “the receptionists need some training. They can’t hang up on people when they’re on the verge of killing themselves. To not be so dismissive. Even if the person isn’t that nice to them, it’s not personal or aimed at them, they’re in crisis, they’re in distress”; “once you keep ringing them their behaviour seems to change. Often you have to keep ringing to get anything out of them like an assessment”.

Other comments were specific about the experience with ALPS: “triage nurses: lovely and sympathetic; A&E nurses: lovely and sympathetic; ward nurses: lovely and looking after me; ALPS: sterile! No passion or emotion at all. You think you’re getting help up to that point and the hope dies”; “the triage nurses have always been much nicer, reassuring, explaining the process, being caring”.

What do you find helpful when in crisis?

We felt this was a vital question to ask as we wanted participants to consider what they actually need when experiencing a mental health crisis. Simply asking for 'help' provides no direction to the staff which is something that was pointed out to the participants.

Some were able to express their needs readily: "a strong sedative"; "a quick response"; "leading with questions instead of 'what's the problem?'"

Some responses were more general such as "the human touch" - "telling us a few bits of info about themselves (Crisis staff) if we're into conversation. So we feel we're talking to a human not a machine"; "someone who will listen" and "sometimes the little things can help, some distractions, talking". It was recognised that this could "really vary depending on the situation or type of crisis".

The value of distractions was discussed: "they can sometimes be useful, other times they're just a hindrance because it's all still there", "starting a conversation (with Crisis) such as about pets and hobbies (can be helpful). If the person responds of course. With some people that will work as a distraction. Must be gauged carefully".

It was felt that a more holistic approach taking both physical and mental needs into consideration was very important; e.g. a menopausal lady will have added issues due to hormones; if someone takes in their mental health medication as they're supposed to, to be allowed to take them when required, not withheld because the A&E staff are not familiar with them (in one case for hours while they tried to get advice from the pharmacists).

There were lengthy discussions about everybody's individual needs. In some cases they relied more on friends and family or a support network of people "who recognise how bad I'm getting and reach out to me" and, if at A&E, to be asked if they'd like someone from that network to be contacted, especially when presenting alone. In quite a few cases frequent contact with their GP, especially when they consistently see the same GP, or similar (in one case the participant required 3-monthly checks about physical issues but their mental state was also recorded) helps keep track of their fluctuations, not to mention these professionals are able to spot some of the early warning signs. There were often cases when the GP's could spot a crisis coming up which despite their efforts, still didn't result in a good outcome: "I ended up feeling sorry for my GP who was despairing with the treatment I was getting. All she had been told to say – ring crisis, go to A&E – was being followed up but it was all turning into disasters".

It obviously requires a support network of people who know one well enough to be able to recognise any deterioration in mental health. It was recognised that the Crisis and ALPS staff are in a severe disadvantage here because they do not know the person in crisis, or have only had contact with them when in a poor mental health state and do not have a baseline of how they are when more stable: "communication so they get to know me a bit because they don't know me. Finding out more about me can help them figure out what to suggest. Taking the time, caring enough to get to know me. To make me feel like someone is listening and caring" or "ask our family and friends, if possible, how we usually are and how bad they think we are at that moment. You don't know me, you don't know how low this is for me" and "ask 'who needs to know you're here? Can we ring that person?'. Also it's important "they know I don't have anybody, I don't have an emergency contact. Then they don't ask if I've spoken to my parents or my family which is a very upsetting topic for me".

"To be dealt with people who can think out of the box, who are flexible and ask better questions". The nature of the questions and the type of communication were brought up a number of times: "more open ended questions. Yes or no questions about personal care leave no gap for someone to disclose they are about to make an attempt on their life"; "it helped to be asked what I've tried before if I remember. I might not due to the mental fog, but it's worth a try"; "asking 'what

are the most important things in your life right now' not at the start of the call but further in, like 10 minutes"; "ask me 'what is bothering you the most, right now?'" "Not to be asked how I feel. I cannot answer (due to autism). Just be with me. Instead of asking me 'how can I help you?' give me options like 'can I hold your hand?', 'do you need a drink?', 'would you rather I sat opposite or next to you?'" "instead of asking 'why are you feeling this way?' maybe ask for the triggers. I've been asking why all day"; "the whys make me doubt my sanity"; "possibly asked 'do you know what could calm you down?' If I can't answer, give me options, make suggestions to me... to calm me down enough to be able to answer questions... Try distractions with me or counted breathing. I often don't know what triggered me" but "don't tell me to calm down and breathe". "Ask me if I'm autistic. I may not have an 'official' diagnosis and it may not be in my file". If dealing with someone who has dementia "ask 'where are you now?'"

One angry participant wrote in the survey "not to be sectioned and locked up like a ****ing animal. You may think you are keeping people 'safe', you are contributing to long-term suicidality by dehumanising people in this manner. Coming away with an actual plan for treatment and not empty promises just to get people to go away. Some actual ****ing medication like Valium – you don't deny morphine to people in agony, so why is it OK to keep people in mental agony just because you can't see the cause? Literally, just the opposite of what you already do!!!" Another expressed their frustration "I've not found anything helpful with the Crisis team. But it would help if I was given time to talk and not be told to 'have a bath', 'go for a walk' and if I don't do these things don't tell me I'm not engaging and you can't do anything else".

A place of safety people can go in times of crisis was often mentioned as "somewhere safe I can go any time". This varied a lot from:

- admission to hospital: "admission in the CAU⁵ because I often come around pretty quickly but still need admittance", "some way to keep me safe for a few days";
- emergency respite: "to mingle with people and de-escalate the crisis quickly", "for a few days with staff on site that I can talk to and not be by myself. Something in between Becklin and planned respite but away from home"; "planned respite is not an alternative to emergency admittance", "I cannot plan my crises 3 weeks in advance to book respite".
- "ICS⁶ "unit based treatment", "ICS home treatment isn't for me. Money spent on ICS would be better spent on safe spaces";
- "being somewhere different to help me break the cycle of thoughts"; "to be with other people and just talking which is why I like Dial House. Crisis is a bit of an abnormal state so to be put in a more normal situation is helpful". "There needs to be a level between managing and crisis when the build-up starts. Sooner de-escalation. To feel part of society by being with people who understand. Being able to talk at that stage, especially when I don't have anybody to talk to, can make a difference".

For single parents the options are even more limited: "somewhere quiet to go. Somewhere I can be away from my child, even though this sounds awful. But knowing my child is safe but I don't have to look after him at that point. Something to eat, drink, something to help me sleep. I make sure my child gets what he needs but I have no energy to look after myself".

For some participants reassurances that the situation will not be taken out of their control would be helpful as well as "having things explained (by the police and paramedics), what will happen so I'm not frightened"; "full explanations about what is happening, where I'm being referred to, what will happen. Knowing helps me calm down. They say I'm overthinking but this knowledge

⁵ Crisis Assessment Unit

⁶ Intensive Community Service

helps me. I like to look for solutions and understanding. It's not ruminating, it's problem-solving. Being told 'don't worry about that' makes me worry more about it!"

Things that would exacerbate the situation are feeling like being discriminated against "BPD is so stigmatised that I often get dismissed", "being told I'm a burden on the NHS makes things really worse", "it's worse asking for help and not getting it than not asking at all. Wear and tear and costs escalate" and to feel like their poor mental health state is not being acknowledged "if I'm extremely agitated and wound up I don't want to see them (ALPS staff) wondering around, taking 10 minutes to check if the little room is free which is just around the corner. They had already seen me badly shaking. This laid back attitude does not help me calm down, it makes me more wound up". Being passed from one service to another is guaranteed to make the person feel like nobody cares: "my GP insisted I contacted Crisis. I got passed around: Crisis said I needed to ring CMHT, CMHT said I was with psychology and I should ring them, psychology said I should ring Crisis and they said they were too busy to ring me back. I ended up in hospital".

Medication to help them through the next few hours or days was considered helpful such as sedatives or sleeping tablets. Combined with accurate recording misuse could be easily avoided.

Having some kind of follow up, for example when someone has hurt themselves badly enough to go to A&E, even if they self-harm very frequently: "why did I do it that bad? What has made me hurt myself worse than usual? There is a reason. They don't follow it up. Because the reason I hurt myself that bad was because the alternative was to take my life. But they don't pick up on that point". Or "a phonecall a couple of hours later. Agree the time. If I say I'm about to just go straight to bed, ring me the next day". It was argued that "if you have a family and a house and a job and a car they assume you don't need any support after the crisis".

An easily accessible care plan stating known triggers would be useful or more specifically if contact with the Crisis team is made "they need to ask me how I'm going to manage without their assessment so at least we can make a safety plan".

For those participants with bi-polar who are in more danger when manic it was a lot harder to think of what could be helpful "the only thing that works is letting it die down. But I can't be held down in any way. Then I'm likely to lash out. Maybe access to a gym to use up all that energy".

There was a lot of demand for a quiet area at A&E: "my personal space is trampled especially when A&E is busy. I am more likely to lash out but I'm just defending myself because they're in my space not because I'm normally violent"; "an autistic person's meltdown can be interpreted as being violent or psychotic. The quiet room would help someone not reach that stage"; "an environment that will help me calm down a bit so hopefully I can talk to ALPS by the time they turn up"; "a safe, quiet area. Nobody checks up on you in the general A&E area. Don't wait for me to ask for a quiet area, offer it to me"; "a quiet place with some distractions. No TV. Fidget toys, quiet toys, a choice of simpler and some a bit more complicated, Lego, Playdough to make things or just squash it, stuff from the charity shop. And someone checking up on me. Drink and food, basic stuff. All that could result in falling asleep and maybe calming down"; "in a quiet area distractions like pen and paper, colouring things, not TV, some toys that require a medium level of concentration, not bright but not dull, relaxing, a drinks machine. In that environment you can ask people what else they'd like in that room. Things that can be picked up from a charity shop, no huge investment"; "softer lights and colours", "a comfortable chair, a soft toy, something to hold or keep my hands busy, someone to pop in every hour and check up on me". Such an environment could make a significant difference in de-escalating".

Alternatives to the current style of verbal communication while being assessed by ALPS were suggested: "ask me questions where I can pick from 1 to 10. But they need me to ask me what I'm like when stable to get the base line"; "ask 'are you able to tell me?' I'd shake my head. 'Could you

write it? Could you draw it? And come up with alternatives. Have a communications tool box: pens, paper, colouring stuff, flashcards"; "even if I can't communicate verbally or written, I can still draw something basic"; "colouring pens may be insulting to one person and a god-send to another"; "give few choices, use alternatives presentations and methods to ask, maybe using flash cards. Maybe 8 emotions and they can pick a couple. It would be much easier than answering how are you feeling. As long as the cards aren't patronising. If someone can't speak that would be very helpful. We're expected to be able to speak which is so hard. And we force ourselves and based on that fact – that we can speak in a fashion – we are dismissed as not being in crisis". "Some people use apps. Ask them if they use something like that. Give us alternatives". "Some resources in a box ALPS can grab on their way to A&E" was a very good suggestion "also for people when English isn't their first language. Quicker too. It would give the staff quick direction instead of asking pointless, annoying questions".

Allowing more time to respond could make a big difference to some "it may take me a while to process it (the question) and get an answer together. If you re-phrase it while I'm doing that I need to process the new question which will take even longer. I may hear as an adult but only be able to respond as a child". Perhaps asking if the person in crisis has understood the question instead of assuming they haven't and rephrasing it would solve this issue.

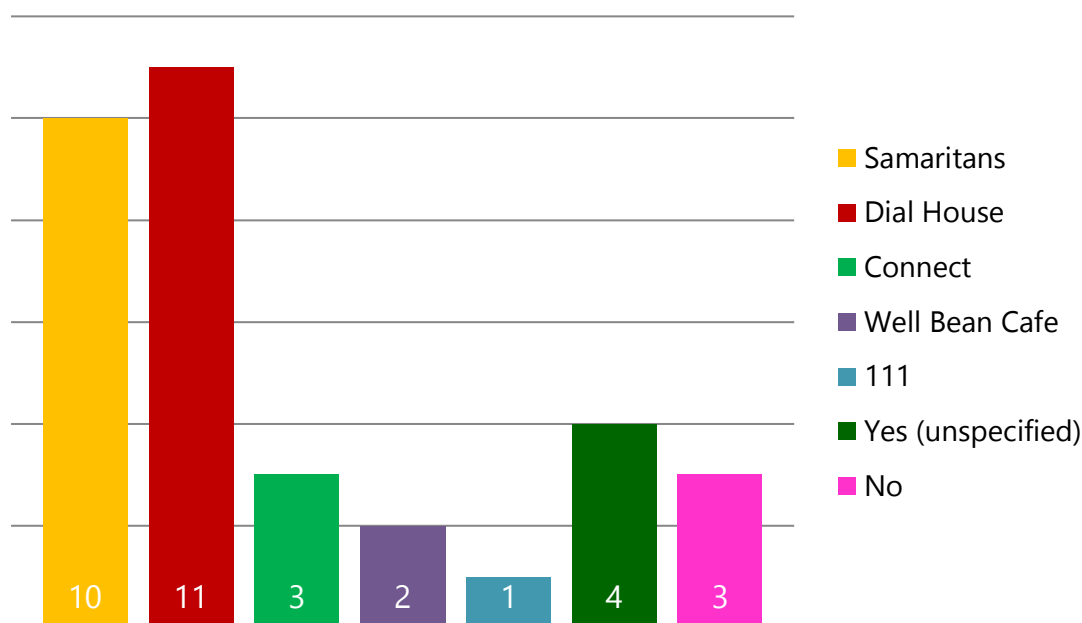
A completely separate mental health A&E was a suggestion that was made a few times as well as the idea for that to be located at the Becklin Centre even though it was acknowledged that some people could find attending the psychiatric hospital when in crisis very daunting especially combined with the myth that those who self-harm get sectioned or the fear that any such action would result in their children taken away from them.

The value of a 24 hour care / advice line was also discussed as an option between Samaritans and ringing Crisis especially after the Connect helpline is closed for the night: "someone I can talk to who will not freak out if I'm self-harming and who are available during the day time. I self-harm when my child is at school. I cannot ring Connect or go to Dial House".

Are you aware of other services that offer support in times of mental health crisis?

Even though the majority of participants were aware of some services it was surprising that some simply did not. Also even though quite a few were aware of Dial House they were not aware of the Well Bean (Crisis) Café and some of those who had heard of these services had yet to try them out. Many asked us for more information which we were able to provide (leaflets for both services were available at all focus groups). The participants and the focus groups facilitator also expressed their personal experiences of these services.

Awareness of other services
Total responses: 22
 (some aware of more than one service)



Some comments about these services included “they’re lovely and helpful (Dial House)”; “brilliant model but not enough (Dial House)”; “I’m sure they would be great if you only experience crisis between 6 and 7 pm on a Wednesday for instance”; “I’ll try Dial House or the Crisis Café before ringing Crisis now. I wasn’t aware of them before. But the set opening hours are a problem”; “I’ve rang Samaritans but didn’t find it helpful. I tend to ring Connect or try Dial House”; “Samaritans if I need to talk”; “I’ve used Samaritans. I had heard of Dial House but never tried them. I was not aware of the Crisis Café”; “even though many people reach crisis point later in the day, that is not the only time someone hits that point”; “it would be fantastic if Dial House could expand on what they’re doing”.

The general opinion was that “GP’s are not aware of Dial House or the Crisis Café. They think Crisis is the only option”. But one GP who took part stated they were aware of these services “and often I have advised people to use these rather than Crisis as someone to talk to as Crisis may not have time to talk at length with a person as they might want. I have signposted to Dial House and Samaritans a lot for this”.

General comments made during consultations

There was a level of frustration linked to where someone can turn to when struggling and certainly before reaching crisis point: "I don't want to be told to contact IAPT⁷ all the time who find me too depressed to help and tell me to get other support. But what? Too high for one service, too low for another!"

Similar frustration was expressed regarding different assessments and their outcomes: "Having to go through assessment after assessment, telling the same story. In the end I'm churning it out and it doesn't even sound bad to me anymore! Even though it is"; "this year I was called to an assessment at the Becklin. I was an inpatient 10 years ago. They said 'we couldn't help you before, we can't help you now'. It was 10 years ago! I'm in a different place now. I needed this to work! I was discharged at the point of referral and now my GP is struggling to find some support for me. I was told I was beyond help. Thanks..."

Many participants were not aware if they had a crisis plan and if they did where it was kept. "If I'm led to believe I have a crisis plan I expect this plan to be logged and found when I need it. They didn't believe me when I told them what my crisis plan was. I was told to ring the police".

A dissimilar approach between services is something that was brought up: "I had 2 police, 2 paramedics and 2 Crisis team staff in my flat. Police and paramedics said they couldn't go yet due to risk. Crisis staff were leaving after she said she'd hide my tablets in the kitchen! I ransacked the kitchen as soon as they left! Telling me where she hid them was stupid".

About needing longer term support from the mental health services "being independent, being able to get on a bus, doesn't mean I no longer need support".

One participant following their assessment after which no action was taken commented that they were chased out of A&E despite declaring they were unsafe being home during the night. Other comments about A&E included "it's OK they ask if we've had any alcohol but saying no and being treated as a drunk is not acceptable" and asking for a "calm, simple response from the A&E receptionists. I feel silly enough. Once I've presented the Mental Health Crisis card⁸ they can just ask me if I've hurt myself or if I'm suicidal".

There were a number of comments about better trained staff on issues such as self-harm and autism and questions such as "do the staff get trained by people with experience of mental health crisis?" and "how about peer support at A&E? As a longerterm plan. People who have been in that position and understand".

⁷ Improving Access to Psychological Therapies service

⁸ See next chapter

Mental Health Crisis Card

The idea of being able to carry a card with basic but extremely important information about the person experiencing a mental health crisis originally came from the Battle Scars peer support groups. They requested something that could be filled in while the person is in a more stable state and able to explain what they find helpful in order to start calming down. Commitment from NHS staff – crisis services as well as A&E – police and paramedics that this card will be taken into account will be vital in making this aid work.

A draft version was taken to all the focus groups and the following is the proposed version. Folded in half, this card is the size of a business card.

Page 1 - front

Crisis Card

My name is:

My address:

Please ask for my D.O.B. – not on card for security reasons

GP surgery:

Please ask me if I've hurt myself or if I'm suicidal

Page 2 & 3- inside

I struggle with:

Medication I take:

Please consider this:

What helps me:

Page 4 - back

Who needs to know I'm here (name and contact number):

Other important information (e.g. allergies, I'm autistic etc.)

www.battle-scars-self-harm.org.uk



fold line

Battle Scars statement

We were fully aware that the majority of people who partook in this research would have negative experiences with the services. We acknowledge that there are also a large number of people who have received excellent, good or adequate support. Our aim with this report was to highlight the issues so even though its content is mostly negative it also provides ideas and suggestions on how to improve the services.

Constraints linked to resources were explained throughout this process in all face to face discussions as well as the actual current size of the Crisis team who respond to calls through the Single Point of Access (SPA). Such information, even though received with shock and disbelief, provided participants with a clearer image and we hope will also help them be more understanding towards the staff who are dealing with them.

Battle Scars group facilitators, other volunteers, staff and trustees will continue gathering service user feedback from those who use the crisis services. It is our sincere hope that we hear of more positive experiences and that we can continue working with the NHS and other services to make good use of such feedback.

Summary of suggestions

The following is a summary of suggestions that were made in this report:

- Clear criteria on what is considered a crisis (non-changeable)
- Texting, email or video (Crisis service)
- Review of call-back waiting times
- Review of timescales:
 - Clear
 - More definite
 - Realistic
 - Regular updates (at A&E)
 - Same response irrelevant of who rings (person in crisis, partner, friend, professional)
- Places of safety – more options
- Better communication while waiting (A&E)
- Quiet area at A&E:
 - Basic drink & food provision
 - Checking up on those waiting
 - Comfortable chairs
 - Distractions (e.g. soft toys, fidget toys, medium complexity toys, pen/colouring pens/paper)
 - Soft lights and colours
- Separate mental health A&E
- Easily accessible care plan & crisis plan
- Use of Mental Health Crisis Card (or similar)
- Staff training (e.g. autism, self-harm)
- Staff training by people with experience of mental health crisis
- Assessments carried out during the night (by Crisis)
- ALPS assessments possibly carried before physical injuries are treated if not serious
- Choice given to be assessed by ALPS or not (following treatment of physical injuries)
- Staff explaining their role and skills set (ALPS assessment)
- Holistic approach taking into account physical, mental health needs and care already in place
- Fewer assumptions:
 - Ability to answer questions is not a reliable indicator of mental state
 - Previous history not to be used as a safe way to gauge current intentions
- Attitude and responses:
 - Attentiveness
 - Caring
 - Compassion
 - Consistency (extending to decisions made by staff on different shifts)
 - Courtesy
 - Dignity
 - Empathy
 - Flexibility in approach
 - Friendliness
 - Genuine responses
 - Honesty
 - Looking past self-harm to look behind it
 - Non-judgemental
 - Not being patronising
 - Patience
 - Professional approach
 - Reassuring
 - Respect
 - Sensitivity
 - Sincerity
- Questions & suggestions during assessment:
 - Alternatives to verbal communication, resource box (write, draw, flashcards, apps)
 - Better balance between questions that are too closed and questions that are too open.
 - Choices kept simple
 - Clearer explanations for person to retain control
 - Direct questions
 - Fewer yes or no questions without opportunity to elaborate
 - Inquire about intentions
 - More time allowed to respond/ask if question was understood
 - Questions that can be answered on a scale of 1 to 10
 - Questions that will allow staff to know the person better (involve family/friends)
 - Questions that will indicate whether short-term or long-term assistance is requested

- Remove certain suggestions from list (walk, cup of tea, bath, book)
- Option to talk to ALPS staff with or without person accompanying
 - Consider possibility of prescription of sedatives or sleeping tablets combined with accurate recording
 - Explain and notify if other services will be involved (e.g. social services)
 - Quicker assessment following admittance to wards (before discharge)
 - Cessation of passing around to different services (Crisis, A&E, police etc.)
 - Follow up with a phone call or with community teams
 - Accurate information provided about other services
 - 24 hour mental health/advice line
 - Longer opening hours for Dial House and Well Bean Café
 - Making GP's aware of Dial House and Well Bean Café
 - Fewer assessments
 - Unified approach from various agencies (police, paramedics, Crisis, ALPS)
 - Calm response from A&E receptionists
 - Peer support at A&E



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