## **Out of Hours Crisis Support**

People across East Lothian who have experienced crisis came together to look at what's missing and what would make it better.

People told CAPS that this is what is important to them...



CAPS worked in partnership with Penumbra, Changes, First Step and Stepping Out to organise events in East Lothian so people could talk about this topic.













### What is CAPS?

CAPS is an **independent advocacy organisation** for people who use or have used mental health services.

CAPS works with people who use or have used mental health services as individuals or as members of a group to set their own agenda, to find a stronger voice, to get their point across, and influence decisions which affect their lives.

CAPS provides individual and collective advocacy in **Midlothian** and East Lothian. CAPS also has several Lothian-wide experience-led projects.

**Individual Advocacy** is about working **alongside a person** to help them **express their views** and have more **influence** over **decisions** being made about their lives.

Collective Advocacy is about groups of individuals with a common cause who come together to raise awareness, campaign and influence service planning and provision.

CAPS is an **Independent Advocacy** organisation.

This means that it:

- Puts the people who use advocacy first
- Is accountable
- Is as free as it can be from conflicts of interest
- Is accessible

CAPS is a Scottish Charity, Number SC021772

CAPS is funded by East Lothian and Midlothian Councils, NHS Lothian, and East Lothian Community Health Partnership.

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## The story so far....

In 2012 following the introduction of 'A sense of belonging', Lothian's joint mental health strategy, each area of Lothian devised an Action Plan.

Within East Lothian's action plan the following action point was identified as one of the short term objectives;

#### 'Improved access to crisis services and supports.'

CAPS carried out a comprehensive study in the year 2012 that identified several areas around this topic that confirmed this was a priority for people;

- 71% of people said that they had been in crisis at some point in their lives
- 62% of people said that face to face support in these times would be helpful
- 55% of people said that contact with somebody in a different form would be useful
- 45% of people said that contact with somebody who had experience of what they were going through would be beneficial.

In 2013 CAPS produced the report 'Places to go, People to see, Things to do'. Again within consultation for this report people identified crisis support in East Lothian as being something that was missing.

- Support from mental health professionals someone to talk to one to one
- Services where you are listened to, get help when you need it and are easy to access
- Crisis and emergency services

In 2014 CAPS held an event 'The People's Conference' in order to take people's opinions of the progress of 'A sense of belonging' to take to the NHS annual 'Taking Stock' event. At this event, gaps in services were identified;

- Have more drop-in centres
- For services and venues to be accessible
- There needs to be out of hours, outreach, crisis and prevention services across Lothian designed around people's needs not professional's hours.

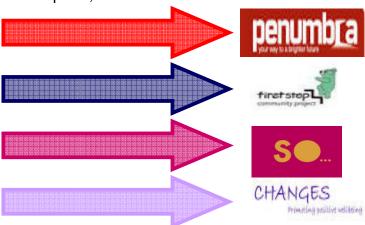
## Where we are now.

In 2014 it was recognised that there was still no out of hours crisis support in East Lothian outside of the National Help lines like Samaritans and Breathing Space. A steering group began meeting to look at the options in East Lothian to provide crisis support.

East Lothian Council along with 3rd sector organisations and NHS began looking at what had been provided in the past and what the options for service provision could look like going forward.

CAPS offered to undertake events throughout East Lothian to find out what people who were going to use a service wanted and what would and wouldn't work for them.

#### At this point;



CAPS, and people we work with, organised the events that form the content of this report.

The events were organised;

- Throughout East Lothian because people told us that getting to places was difficult, especially with poor public transport;
- In the evening as well as during the day because people told us that they found it difficult to attend if they were working;
- Including childcare at one of the venues, because people told us that they found attending meetings difficult when they had children.

## What did we ask...and why?

The events were designed to be as open as possible for people to discuss out of hours crisis support in an unrestricted way. To enable this, at each event there was facilitated discussion, as well as post it notes and markers to write down ideas and anonymous feedback was allowed for with envelopes and notepads.

The facilitated discussions looked at 3 main questions, mainly to fuel ideas on what people wanted and allow for the most varied responses;

## What supports do you use at the moment? What is helpful?



## What, if anything, is missing from the support you use just now?



## What could be done differently to make this better?



## What did people say?

There were 46 people in total that came along to the events, 18 men & 28 women. There was a wide age range and a good mix of experience and backgrounds.

# What people said about supports they use at the moment;



"The GP phone service we have in North Berwick is really helpful....it could benefit other towns in East Lothian."

"Peer support from family and friends"

"Stepping out"

"Friends and family....someone you can rely on to speak to"

"CBT is helpful"

"Our facebook page for our group is good...support provided is safe and comforting"

"Voluntary organisations"

"IHTT, but you have to be referred"

# What, if anything, is missing from the supports you use just now?

When we asked people to tell us what was missing from the support they used just now there were lots of different areas that caused problems for them, so these have been thematically linked;

## What people said about access to current services;



People said that waiting lists were a huge problem when trying to get help. The felt that this often led to them reaching crisis because they had waited so long to have access to other services;

"Services are too busy...resources are stretched.... this means that we aren't able to get the services we need when we need them."

> "For certain services you have to have a certain level of 'wellness' to access them"

"Can't get a GP appt, always few weeks before any availability"

"Once you access services they are excellent...it's getting there that's difficult"

What I want...need is ACCESS to counselling not long waiting lists!"

"Urgency can disappear with long waiting list."

### What people said about transport;



People said that getting about East Lothian was very difficult, especially in the evenings;

"If you suffer from anxiety for example there is no way you would take two buses to get to a drop in."

"Somewhere on a bus route...travelling is hard"

"You need somewhere you can get to late at night, it needs to be local"

> "It would have to be in Haddington as I don't have transport"

"Having to go to the REH at 11pm for an assessment is not possible...How would I get there?

People from Dunbar said that they felt that all the resources were centralised and that there was not enough provision for them;

"Everything is in Musselburgh/Edinburgh, can something not come here?"

#### People talked about the idea of one building being impractical;

"One purpose built building wouldn't be helpful as transport across East Lothian is very difficult."

> "I would find it very difficult to get a bus to a drop in centre that was not in my town as suffering from anxiety I would stand at a bus stop for hours and still not get on a bus."

"If the service was mobile you could first chat to someone over the phone and then arrange an appointment face to face when the service was going to be in your town."

> "If there was only one building it would be good to have local drop-ins in each town...early intervention that could then refer to the main hub."

# What people said about privacy, respect and continuity;



People spoke about the importance of continuity. They spoke about how frustrating it is, having to tell their story over and over again. There was an emphasis from all the events around the need for privacy and respect, people felt that services did not appreciate the need for this and felt that stigma was still a big part of how people with lived experience of mental health were dealt with.

"Receptionist can be difficult at GP...lack of privacy...Respect can also be an issue."

"Consultant who actually saw our son had not read the background info that had been given by another consultant, therefore didn't know his history."

> "Consistency in support is a big thing...something you can rely on when a crisis happens."

"Lack of consistency when going to the GP, would be helpful if they all had up to date info about what was happening."

"Support can often be patronising which is the last thing you want."

## What people said about support for Carer's and families:



People told us it was difficult when they were in crisis to know what to tell their children. They were concerned about the lack of support available for their family and friends. People who were carers told us that they feel isolated when the person they are caring for is in crisis.

"There is no information available to give to my children to help explain what is wrong with me...support around this would be helpful."

"My dad couldn't speak to me when I had a breakdown...he didn't know what to say." "You need somewhere safe that you can take your kids with you"

"Support should be available for parents/carers as well."

"....Support from one service for parents and another for my child, why can't one service support us as a family?"

## What people said about 'information';



One of the things that people spoke about the most was the need for information. Some people felt that services did not have accurate and up to date information, whilst other people felt that information was too difficult to find. People said that services needed to be more joined up with information and that one central place or person to contact would be good.

"Better education and training in mental health is needed"

"There is no accessible person that has info on what's available....someone with their finger on the pulse!"

"Better signposting is needed. It's hard having to do all the leg work yourself to find services that might help." "More info – GP's don't know about support services available"

> "If you are in crisis you can't be bothered searching the internet for help...you want something immediate and accessible"

"Hospital did not give any info on things like advance statements." "Services are not very well known there should be better information sharing."

"Although East Lothian is large geographically, community wise it is quite small. It would be good if mental health terms, GP's etc, linked up and advertise available supports...sometimes there is just a lack of information."

# What could be done differently to make this better;

We asked people to think about what could be done to improve the issues that they had with current services. Again the comments from all 5 events have been linked by theme in this section;

## What people said about drop-in's & phone lines;



There was a real divide in peoples' thoughts about how drop in's might work as part of a service. Several people said that it was key to have a drop in available but the logistics of this were complex. Some people felt that one building was impractical, others felt that it was necessary to fulfill the requirements of the service. People had mixed feelings about phone lines as well. Some people thought that a local phone line would be ideal, others talked about how the phone can be difficult for them to express their feelings. People came up with several ideas and proposals for this;

"Having a local first point of contact would be good."

"Phone lines are not particularly helpful as you feel like every time you call you have to repeat yourself."

"A community centre, library or local sports centre would be a good place for a drop in."

"Something like a social enterprise café would be good...It wouldn't have to be mental health specific but would give people access to things that might prevent crisis."

"Could be mobile...once a week...a sort of popup drop in?"

"Somewhere that had other activities."

"Somewhere available between appointments while you are waiting on referral lists."

"Would like a drop-in with qualified staff that can handle crisis situations."

# What people said about when the service would be useful;



When we asked about when a service like this would be useful people said that in the absence of anything else it would be useful during the day as well as out of hours as people said it was difficult to get appointments at anytime.

People spoke about the fact that evenings and weekends were hard and that they felt national phone lines were impersonal.

"Night time, after the kids are in bed."

"Something that could be accessed from home at any time of night."

"Ideally it would be available 24 hours a day, it is hard to get appts anytime." "When you are in crisis you don't sleep...something needs to be set up for evenings."

"I have phoned Samaritans at 4am just for someone to talk to...this helps me."

# What people said about what should be included in the service;



People talked a lot about the elements that would be important to them in a service dealing with crisis.

People talked about who they would like to be involved with a service. Some people spoke about what things they would like to see included in a service.

"A buddy system would be good to help with crisis prevention."

"Somewhere that had a mix of staff...peer and professional...men and women."

"Somewhere that offered support groups that were quite unstructured."

"An online source that had up to date information."

"Education, training and volunteering opportunities...WRAP etc."

"Something with a Christian ethos...somewhere that wouldn't turn you away."

"Somewhere with options for people... group activities or one to one space."

"A familiar voice at the end of the phone."

"People working in any crisis support have training...are calm...that they bring something to the support."

## What people said about peer support;



People spoke about the importance of peer support as an element within any service. People said that the empathy and understanding of somebody that had shared experience of crisis was invaluable.

Some people thought that a professional element was necessary others felt that the less medical it was the more comfortable they would feel.

"Peer support would be very effective in a crisis situation – but I would like them to have had some training."

"Speaking to someone who has been through something similar would help."

"Peer support is useful as you can share without feeling like you are being a burden...there is an understanding of what you are going through."

"Once the professional help has gone, would like to maintain meetings/social groups. This is where peer support is useful."

"My peer support group is great, but we are not professional there is still a gap."

## What people said...thinking out of the box;



People were enthusiastic about ideas that are not in the traditional toolbox for services. Some people spoke about ideas surrounding social media as a way of providing ongoing support.

Some spoke about the idea of mobile drop in services as a solution to having the restrictions of location.

People spoke about not having one more service that was in isolation, that using it to signpost and act in prevention or for supporting to set up peer groups.

It was felt by some people that it would be good for a service to have a stepped approach where you could access at different points of wellbeing.

"Facebook works because we know there will always be a response."

"A service with a stepped approach...so that you can enter at different times of crisis."

"Crisis can take a long time, so it would be helpful to have something that could help you move on as well."

> "Something that was mobile...a travelling bus? This would mean that places and times could be tried out to see what worked."

"There's nothing in between home and hospital...something to recognise that we are not so ill we need to be in hospital, but doesn't mean that we may not need extra support."

"More creative ways of communicating...social media...phone apps."

"A website that you can login to and only registered users can see information or anything you post."

"East Lothian Social Crisis Network." "A form of follow up included. If they knew something was going on and had not heard from you in a while having someone call and just check in would be good."

"Facebook would be good for engaging with young people." "Somewhere that had activities, groups and social activities."

"Something that was mobile – could rotate a week about in each town."

"Would be good if a medical professional was involved in a facebook site set up...Someone you could raise concerns to?"

#### What were the main themes of the events?



There were several clear themes that came through in these events;

#### Somewhere local;

People spoke a lot about the need to have something local out of hours in times of crisis. There was a lot of discussion about what this meant and there were several different options spoken about although the recurring themes that came through about what this should look like in any location were;

- Regular
- Consistent
- Safe
- Transparent

People like the idea of having a service located in a comfortable environment that had positive associations and that was not specifically linked to mental health to avoid judgement and stigma.

Some people felt that one central building that was available with other activities happening and would be available throughout the day as well as evenings would be a good thing, and that outreach drop-in's in local areas could be run from this.

### Local phone line;

People said that a local phone line would be useful. Something that could be accessed late in the evening and weekends, but that did not mean having to leave their home if they were too anxious or had other concerns like children at home.

People said that talking on the phone was easier for them, but that repeating their story again and again was frustrating, so access to a drop-in that could be arranged through the phone line would be good.

Other people said that phone-lines were difficult for them because they struggled to get what they wanted to say out quickly and found it embarrassing and that face-to-face contact was much more calming.

#### Peer/Professional

There was a strong feeling throughout the events by people that peer support was an important part of any service.

People said that having someone to talk to that had an empathy for what they were going through was crucial, and it felt authentic.

People said that they did not want more medical intervention and that tick boxes and questionnaires would be very off-putting.

Some people thought that a mixture of peer support and professional was an important distinction so that they felt there was someone who could action something if it was needed.

People said that they would want peer support workers to have training and support.

Some people preferred the idea of having a more professional staff as they felt that peer support might not be able to deal with their crisis.

### • Information provision;

People felt that there was a real disconnect with services at the moment and that often professionals did not have the same information or it was out of date.

People said that part of any service it would be good to have somebody that was up to date with ALL services, events and activities that were going on to give out to people, "someone with their finger on the pulse"

### Support for family, friends and carer's;

At several of the events it was highlighted that any service should be available to anybody and should provide support for family and friends of people who are in crisis as well.

People told us that a barrier to accessing any services was childcare and that it would be good to think about this when providing a service.

#### Times of service;

People told us that ideally this would be available 24 hours a day as services were often difficult to access during the day as well.

People said that evenings and weekends were the most difficult time for them

#### · Filling the gap;

People felt that any service should play a role in prevention of further crisis as they felt that long waiting lists were a big part of why they reached crisis.

#### Social Networking and Online facilities;

There was a lot of discussion around the benefits of social media and how this could be incorporated into any service

People said that a secure facebook site that members could access would allow them to build up networks of peer support and work well as a preventative measure.

People said that it would be good if there was access to a professional through this route.

### · A tale of two services;

There was discussion within each of the events about the need for two services. One that dealt with immediate crisis intervention and one that dealt with prevention and ongoing support.

People felt that the lack of consistent regular support between each period of crisis was a factor in how often they happened.

A place to go that did not have such medical specification on accessing it's service was felt to be an important factor in a holistic service within East Lothian.

## Where do we go now?



CAPS will take this report to the East Lothian Joint Mental Health Planning group to let them see what people have told us about out of hours crisis provision.

The planning group will then be able to review what people have said and use this information to form a plan about what could be done.

We will inform people about what is decided.

CAPS have included a copy of the summary for this report with their newsletter and the full report is available on the CAPS website.

Crisis provision in East Lothian may take time to be realised, CAPS will keep people up to date with any developments that happen.

## **Acknowledgements**



CAPS would like to thank everyone who was involved in the planning, collaboration and organization of these events.

For all those who participated in the events CAPS would like to thank you. It was great to see so many people interested and involved in this topic and some inspiring ideas came out of the events to take forward for the future!

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