# **Out of Hospital Cardiac Arrest** Assessing the Rehabilitation and Aftercare Needs of the Survivor

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### Aim

In June 2014, the Scottish Government took the decision to explore the need for an Out of Hospital Cardiac (OHCA) Strategy. To take this work forward an OHCA Strategic Scoping group was formed. As part of this work Chest Heart & Stroke Scotland (CHSS) were charged with the task of exploring potential rehabilitation and aftercare needs of those who survive OHCA.



## Method

In order to achieve the aim within the recognised time limit (December 2014 – February 2014), CHSS conducted a brief survey of their network of cardiac patient support groups (previously considered Phase IV of the cardiac rehabilitation pathway) to recruit those willing to participate in a focus group. To ensure ease of access, groups contacted were restricted to 4 areas; Edinburgh city centre, East Lothian, Angus and Glasgow city centre. In addition, contact was made with a partner charity in Skye (Lucky2BHere). From those contacted 6 OHCA survivors agreed to participate in the work. The group was made up of 5 men and 1 woman, aged between 48 and 75 years. The time from OHCA to attendance ranged from 6 months to 9 years. Consent to use a voice

recorder was gained prior to commencing the discussion.

The focus group was supported and facilitated by the Voices Scotland programme. Voices Scotland is a training programme which enables people affected by chest, heart and stroke conditions to have their say in health and social care systems. 'Emotional touch points', a story initiating technique employed within the Voices training, was employed to enhance engagement, encouraging participants to focus on their perceived needs and circumstances, post event both in the short and longterm.

A literature review was conducted and the findings were used to identify new areas of interest.

#### Outcomes

From the literature review there appears to be little evidence in the area of survivor rehabilitation and aftercare. What information there is comes mainly from Europe (Sweden<sup>1</sup>, Netherlands<sup>2</sup>) and Australia.<sup>3</sup> Achieving high survival rates does not seem to lead to an increased interest in the longerterm needs of survivors.

**Cognitive Function** – Although short term cognitive impairment has been considered, ongoing subtle changes may not be addressed when returning to what is perceived to be normal life.

"If I speak about something and then half an hour later I struggle to remember anything ... it is quite a problem."

"I do wonder to this day if they would have actually made contact with me or cause I made contact with them and I wonder if I would have been lost in the system (cardiac rehabilitation)."

**Condition Specific Care** – Criticism with regard to cardiac rehabilitation provision was also associated with a lack of individualised care.

Within the focus group eight recurring themes were identified:

**Sense Making** – The desire to gain an understanding of the cause. Although the physiological cause and the events leading up to their cardiac arrest varied the participants within the group sought areas of mutual commonality, seeking shared diagnosis and personal experiences.

"It's a family trait my grandfather died of a cardiac arrest ..... it's on my father's side; quite a few have had cardiac arrests."

"I had a heart attack .....I had cardiac arrest in an ambulance and got brought around, so what; it wasn't a big deal for me."

Acceptance and Adjustment – Having a clearly defined cause promoted acceptance and adjustment. For those within the group who could not identify a cause, prolonged periods of questioning took place. In some cases this has been sustained long term, potentially impeding the individuals ability to accept and adjust to what can be an emotionally traumatic event.

"I got irritated that it happened to me cause I haven't got any history of heart disease in my family .... I still can't to this day believe that.....I don't drink, I don't smoke...and I keep myself fit and eh I was the one that was hit by it." "One thing memory wise is, I can't remember people's faces, so after about a couple of days and you passed me in the street I wouldn't remember you."

**Post Discharge Support** – The lack of sustained support during the transitional hospital to home phase can result in a sense of abandonment. Lack of knowledge within primary care can also cause a sense of desertion.

"I got such good care in the hospital ..... and then you're literally out and you don't get anything."

"I went to see my GP and he said he had never seen anyone who had had an out of hospital cardiac arrest before and didn't really know what to say or what to do around me."

**Cardiac Rehabilitation** – The desire to express appreciation for professional and peer support within 'cardiac rehabilitation' was hampered by criticism of delays within referral processes.

"Phase III worked for me, it was an educated pushing, it was someone to show you what to do who actually knew what they "It's (cardiac rehabilitation) all geared for heart attacks, for cardiac arrest there isn't that much."

"There was nothing in phase III or phase IV groups, cardiac rehab groups, that would cater for what you've had and I had (arrhythmia), they're just not there."

Quality of Life – This was expressed as the ability to sustain activities while taking the opportunity to use the event to make positive changes.

**Psychological Care** – Core to quality of life was the need for both informal support from peers, family and friends, and access to formal support when persistent psychological distress is experienced.

"Every time I got eh twinge, say heart burn, I thought I was on my way out."

"I have only got oneish problem left, eh and that is I still get the doom factor ."

"I went back to see my GP.... and I got therapy ... I was very lucky they saw me within a couple of weeks. What I was effectively suffering from was post traumatic stress disorder."

Chest

Heart &

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Stroke

#### were talking about."

#### Conclusion

Understanding the needs of those who survive OHCA is essential not only for the promotion of physiological recovery, but all aspects of wellbeing which are required to sustain a fulfilling life. Although extensive research has been undertaken in many aspects of OHCA care, little is known about the rehabilitation and aftercare needs of survivors, and how these may be addressed. It is hoped that this brief work will spark interest in this aspect of care, encouraging comprehensive research to be carried out in the future.

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