

## **Patient feedback on early supported discharge 2016**

### How was feedback gathered?

Healthwatch Somerset supported patient engagement to gather feedback from patients who had experienced early supported discharge (ESD).

Four focus groups were held across the county:

21 April - South Petherton Community Hospital

26 April - Williton Community Hospital

3 May - Sydenham Community Centre, Bridgwater

11 May - Shepton Mallet Community Hospital

Healthwatch Somerset staff and volunteers supported facilitation and gathered the feedback to record anonymously.

In total we heard from 19 patients and 20 carers.

The full transcript of comments made can be found in the appendix.

The same questions were asked at each of the focus groups. An overview of the information gathered is below.

### What did you feel you needed most following your stroke?

Many people commented that they did not know what to expect and were in a state of shock or confusion in the time immediately after their stroke.

What people felt they needed most at this time was reassurance and emotional support, alongside practical support around regaining lost abilities and negotiating everyday tasks; using stairs, washing, dressing.

### What support was provided to you by the early supported discharge service?

Many services were listed; physiotherapy, occupational therapy, speech therapy, incontinence nurse as well as carers for daily tasks.

It was recognised that emotional support, encouragement, coordinating care, routine, consistency and information were very important. Care plans, reviews and a timetable of visits were appreciated.

Adaptations to the house, equipment and guidance on how to use them were provided with exercise plans to support this.

## Independent patient engagement support

### Other services mentioned

Feedback was given about other sources of support which were found to be useful: organisations such as the Stroke Association, Stroke Clubs, Compass Carers, Aspire but also extended family and the local community played a part in supporting patients once home.

### How well did the service meet your needs?

Lots of praise was given about the ESD service and the staff, mentioning punctual, supportive, patient and observant teams who listened and addressed all the different needs of the patient and carers.

Some felt that the service ended abruptly or that the service could have been provided for longer.

Some seemed unaware of the difference between the care that was provided to them from ESD and the care that was provided by home care service providers.

### What did it mean to you or your family to be able to go home from hospital sooner?

Many patients felt they would have liked to have gone home earlier still. In some cases this didn't happen because they were waiting for another service such as scans, x-rays or a carer support package to be put in place. For some people it was because medical staff were concerned about risk factors relating to their health and mobility or that of their carer at home.

Most people reported that they felt more relaxed at home, their recovery was quicker, they slept better and were very glad to be home.

Some expressed anxiety about not having support at hand around the clock and of being able to manage the activities that they had been taught in therapy when doing them independently at home.

Patients reported that therapy worked better at home because they were in their own environment, learning to manage realistic activities.

Some patients, particularly those who live alone, reported that they missed the company of others which they had in hospital and felt daunted by the prospect of going home.

### How did you find the experience of setting goals?

Overall the experience of goal setting was seen as a positive one. Goals set were realistic and achievable but motivated patients to progress and keep trying. Goals were set collaboratively with the patient and reviewed. Patients reported being asked what they wanted to achieve and then goals set around this. Unrealistic or challenging goals were broken down into stages to work towards them.

## Independent patient engagement support

Routine and discipline was seen as positive, not letting the patient give up on the goals that they found more challenging.

### What was your understanding of EDS and stroke and how was that supported?

Mixed feedback was received here. Some people reported that they had not had ESD clearly explained, or that they only heard about it when they were due to go home and did not know what to expect.

Some people reported having an explanation early on, receiving an information booklet and particularly noted was a talk at Musgrove Park Hospital which was very well received as giving good information on what to expect and signs to look out for.

Both patients and carers expressed anxiety over the unknown for the future and appreciated guidance and information to manage their expectations.

Family meetings were seen as useful as was involvement of the carer in decision making. Peer support from others in a similar situation was also appreciated as supportive and encouraging.

Some people reported being unaware of the term 'early supported discharge' and found it hard to relate to.

Some patients reported that their GP's were unaware of ESD.

### Views from carers

There was mixed feedback given here. Some carers felt that they had been very well supported by the ESD team, included in decision making and treated as an individual with needs which were independent of the patient. In these situations carers had felt empowered to support their loved one with physio and informed about what to expect, how to manage problems and who to contact for support.

Others felt they would have benefitted from more information and from being able to talk to the EDS staff without the patient being present.

All agreed that caring can be exhausting, that support from family or neighbours is valuable and that the support from the ESD team in the home was reassuring.

### How could the service be improved?

Many felt that the service they received could not have been better.

Concerns were reported about the coordination of visits and the amount of visitors to the house, particularly in the days immediately after discharge from hospital. It was recommended that the service be mindful of the overwhelming aspect of this and to respect the patient's private time and energy levels; to be aware of how tired the patient can be.

There were some criticisms of home care service providers in terms of punctuality.

## Independent patient engagement support

Requests were made for more information on what to expect, who to contact and what alternative support is available in the community.

A coordinated approach is necessary between the ESD team and other agencies involved to avoid clashing appointments and duplication of tests which patients found frustrating.

The amount of appointments leaves little time for the patient to rest or for the family to plan ahead and organise anything else. An acknowledgement of the patient's life outside EDS was highlighted.

An individualised approach to planning – in some cases the patient would like to take control and in others they would prefer that information was given to their carer. It is important to check and not assume.

Training for GP's was recommended as many people reported a lack of awareness from their GP around ESD.

Continuity of personnel within the home should be considered for the patient and their family's benefit.

Consistency around the support given to carers. Where this was reported as not so good it was recognised as a gap in the service provision.

Information and being prepared for the realities of what to expect could be better in some cases.

The coordination of hospital discharge needs to be well managed with cares, families and the community services which need to be in place.

Patients reported being confused and frustrated by the impact of their stroke on things like their ability to write, do maths or remember words and their level of fatigue and feelings of isolation. Acknowledgement of this impact on self-confidence is important.

## Comments on hospital stay

Some feedback was also collected about patients care whilst in hospital which is included in the appendix.