

Appendix - Patient feedback on early supported discharge Notes taken at focus groups

What did you feel you needed most following your stroke?

Needed to do stairs (new rail fitted)

Emotional support, I wasmore tearful but usually when on my own so team didn't know.

I needed routine. I have a full time carer as I have transfer difficulties and also I need the company.

I needed support with reorganisation of the furniture. I had some support from South Petherton. I was very disorientated, not understanding what had happened. I knew exactly where everything was but I couldn't access it.

Generally unknown – I didn't know what to expect.

Initially unaware I had a stroke. Then wanted to get better as soon as possible.

Back up and support and knowing that someone was available.

My priority was trying to get back to normality. I needed something to look forward to, to keep me going – determination.

I needed to get the use back in my hand - I needed to be able to do my catheterisation instead of the nurse, I didn't want a permanent catheter. I needed to find the nurse who could train me.

Returning to driving was important to get shopping etc...don't want to drive far. Team gave me information and set up my return to driving.

Exercise routines

Direction/instruction

Encouragement

Reassurance that we were going to get back to how it was before (x 2)

Wanted to come back home (x 5)

I didn't really know — I'd been in hospital before lots for other things but I was shocked — I didn't know what had happened.

I couldn't accept where I was. When they asked me where I was I said I was in my chair at home. After a few days I knew I was in hospital. I don't remember the journey to hospital.

I had no clear idea of expectations



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

Good from inpatient which then flowed well to home with same team (wonderful) – I had no idea that would happen

Physio and OT – had a package of care but they didn't do as much as my needs. OT's helped independence and left arm. At least three times weekly.

I had two visits from OT. They wanted to come more but I persuaded them that it was language and speaking therapy I would find more useful.

"Finding new way to do things" worked as a team, supported the carer to help the patient to learn new skills.

I had OT, speech therapist, Physio therapy assistant. PT, incontinence nurse, nurse for blood pressure.

The rails in the kitchen on the units are a great help.

I can get into the bath for the first time in five years. The PT taught me the exercises to practice.

I only had a few visits but that was my choice.

The OT picked up on issues like sight, bladder and cognitive – set up clinics for me

I'm still showing improvements. I couldn't do maths which was upsetting. I was worried about paying my bills.

I'm right handed – I had to learn to use my left. I went to the bank to show my new signature for authorising checks.

I had a care plan and a diary which was filled in every day.

At the end of the 6 week period I asked now what? Will I be abandoned? I was told – 'you will never be abandoned'. I have telephone numbers for all of them. The wonderful thing is they are coordinated and someone deals with it immediately and sends it to the right person. This is very reassuring.

I had a succession of people – not all the same and found I had to repeat myself whilst getting to know each other. Had one person who did come regularly and this was beneficial.

Physio, OT, RAs – three times a week reducing to once a week. Understands he's on community but same people – great no repetition and understands why reduced.

Good three times weekly initially – pushed him. They did a good job. Felt he progressed and they had control of it. They were leading it and both understood reasons.

Hospital bed, commode, rails



ESD team – very good support – regular visits – their support focussed on the carer as well

Put in touch with Stroke Association who visited

Laughter brought into house

Making things more normal, impact of the support

Emotional support – have a little cry with carer

Therapy and Physio as well as mental therapy were very good. The staff came at convenient times – they came when they said they would. He felt he was seen as often as he needed to see someone. Initially this was daily, then it went to every 2-3 days. There were also visits at the Weekend and over the Easter Bank Holiday.

The equipment needed by the patient on release was delivered at the right time and very efficiently.

The Physio and OT arranged their visits with the patient.

ESD aided husband with attending to his weak side and aided with reading and with use of computer.

Very nice cheerful staff

Stroke coordinator really made patient 'look at things' and voice feelings/opinions.

There were questions asked about psychological support but I didn't need it.

They try and give you something more to do each time they come. I got very tired after their sessions.

I had a visit the next day

I got all the aids – they order them and they come the next day. Even elastic for exercises.

Speech therapy

Physio

Nurses

The ESD team helped me shower in the morning. They were punctual. They helped me until I could do it myself. They cut it down gradually, from help, to in the room, to at the door, to outside the door.

I has support from PT's and OT's from ESD.

The people who came to shower me knew what the PT's and OT's were doing.

Therapists came and asked if I needed help dressing – I didn't need it.

The nurse would phrase it like -'can you take me out for a walk?' so we went out.



This stroke was not so bad – I couldn't swallow so I had training to learn how to use both sides of my mouth and speech therapy.

I got support going up stairs. The PT's came every day, 7 days a week.

They organised mums treatment and made phone calls.

Other services mentioned

Involved other services ie stroke association

I attended 10 weeks of stroke club. Had talks about — healthy living - depression — how to occupy my time.

I've had lots of carers. I like this one because she is very strict. She makes me do my exercises, this is very positive.

Williton Stroke Club has been very supportive throughout.

I have a fob – run by Taunton Deane. If you press it they call you. If I don't answer they call my 2 emergency numbers. If they don't answer they call emergency services. They have a code to get in. it's £4.99 a week 24 hour service.

We found Compass Carers helpful and the Wiliton Stroke Association positive.

When service ended GP provided input

Lorna Wheeler from stroke Association was very supportive

One person felt more direction to stroke clubs and support groups would help

ASPIRE was excellent 'best thing ever', was good for patients to meet other people and supported the carer. Patient was upset when ASPIRE finished.

Since I've been home the people in the village have been so supportive

How well did the service meet your needs?

Couldn't have asked for more help, Wonderful service.

Speech therapy was very good and very intensive.

They were very punctual – good

It was not appropriate as I was ok with mobility etc – I feel I didn't need it.

The whole team was amazing.

I wrote a letter to Emma to thank each person.



Since at home- feels he had the same people who were all fantastic, physio, assistants, OT all knew what they had to do after weekly meetings and progressed as planned.

Regular visits, especially as lived so far away were, very much appreciated

Helped us to see there was/is a future

Gave him (patient) confidence

Quantity of input was appropriate

Involved partner in exercises – was beneficial

Encouraged carer to go out and leave patient and have a break

Encouraged patient and carer to look to future

Felt ESD team 'listened'

Important having the mood screen and to see if it improved.

Support from ESD 'magnificent'

Felt going straight home from acute hospital would not always be appreciated

Important to have good two way communication between patient and therapists/staff

It was good in the first place, I thought it reduced too quickly (number of sessions) but I know I've got to do things myself.

I missed the encouragement when they stopped, my wife couldn't or wasn't strong enough to support me.

Disappointed this has dropped down as missed attention and interest from someone (don't think needs physio, missed the contact though).

I needed it to go on for a bit longer (3-4 weeks). My wife doesn't feel strong enough to help me.

Back up was wonderful

Mum could do with more help with speech and walking. Could have done with ESD going on longer.

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

No warning of coming home on Christmas Eve – needed to get home.

First visit boxing, Day, three team members, didn't know what to expect, got what she expected. Can't speak highly enough of what they did.



Went according to plan 'beautiful', was as expected, carer made very clear, filled up diary physio etc, didn't know what to expect from - them determined to get better, team helped more than twice a week.

Don't think I did go home sooner by the time I went home I could do most things - up and down the stairs.

Wanted home sooner – I was in for six weeks but going home to be by myself so kept me in.

Gave me a list of who is coming in every day for six weeks – I didn't like this as I felt my independence taken away but my family felt secure that I had the persons in place.

Very lucky – wanted to go home sooner – meds not right – not well enough to go home – kept passing out.

Felt could have gone home sooner but waiting for scans – it was all on the news about the bed blocking- I feel if they were listening to doctors they wouldn't make cuts and there'd be no bed blocking.

I thought I was in hospital for far too long.

On the first day in hospital I wanted to go and see my wife. I would come back the next day. They wouldn't let me go, they told me my life was in danger. They called security. Security came and I got back in to bed.

Relief to be back with people who understood. To be able to fend for self at home. Everyone should go home when it's safe and when carers have worked out what they've got to do.

When he went home he could dictate his own routine – tablets, bed time, morning routines along with wife – felt more comfortable because usual routine.

Emphatically beneficial

Pleased to go home. To stay longer would have taken up bed space and resources.

Own environment – familiar environment – wife at beck and call. re - any medical problems couldn't be answered.

Daunting having patient home earlier

Good to have him home earlier

Worried initially

Progressed quicker, made him do more at home

Motivated the patient

Helped prevent patient from becoming institutionalised

Could have come home quicker



Fear of patient falling

Patient still having visits, but the early discharge was at the right time. He had previously lived independently

Definitely good to be home earlier and the patient benefitted.

Positive to get patient home. ESD input helped tremendously

Someone there within 24 hours as told by staff

Anxious about returning home and supporting at home. 'Like having a new child'.

Discharge home was a lot smoother than they thought it would be

I sleep soundly every night now. Immediately I got home I felt better. Before I kept looking at the clock and watching /waiting for visiting time.

The only challenge was sleeping downstairs to start with. I think I have made fast progress at home.

It was important to my family I come home, they were really pleased when I told them I was coming home. I was still not able to do anything for myself.

I knew as soon as I got home I had to help my wife. I had people coming in to help me but I had to help too.

I was apprehensive for a short time about going home, I was used to having someone when I pushed a button. I took a couple of days to get used to not having a 'button' and knowing I didn't need it. In hindsight, I wanted to go home earlier, but I really wasn't ready. Being able to transfer from chair to chair was important to me.

Mum had heart problems too. There was no push to get her out of hospital. She stayed an extra week as I was on holiday. But then she only had 6 weeks of care left when she got home. Fortnightly visits after ESD would be useful to keep support for longer. When living on your own you need more support and for longer.

I wanted to go home earlier still.

The weekends were horrible.

The carer feels that the patient couldn't have come home earlier because he couldn't walk. Feels it was the right time.

I was in a few days too long because they couldn't sort out carers. There were additional problems which required an operation within 5 days so it was not worth coming home to go back.

Carer has mobility issues so couldn't come home until carers were in place. Told not to try and pick him up if he falls – call 999.

He wanted to come home earlier but they kept him in for the right reasons.



I had additional problems with my back and an aneurism on the brain. I don't understand what happened, what a stroke is.

I couldn't have come home earlier – they got me walking.

I had to wait for scans and x-rays.

Being at home helps recovery.

As soon as you get a bit more mobile you want to get home.

Therapy works better at home. At hospital they didn't have enough time. ESD had time.

It's good at home because it's in my own environment. It's our steps. They put handles and rails. The therapy is tailored to the home and what you need to learn to do. It's more realistic.

I was apprehensive about coming home. Although I had been shown I was worried about whether I could do it on my own at home.

When I had the support at home it gave me confidence to do it by myself.

I was more relaxed once I was home.

I sleep better at home.

How did you find the experience of setting goals?

Goals – what she wanted – patient led

Patient didn't know his goals although wife did but he knew he was progressing and achieved what he wanted despite speed problems.

ESD provided to help negotiate unrealistic goals

I wanted to get back to church – I now go every week, I am the church warden

I wanted to drive – I need an eye test and a GP form.

I wanted to go back to doing what I wanted to do.

Was very encouraging to see daily improvements

I had lots of goals and they worked

- Wash myself
- Tidy my room
- Go up and down stairs
- Make tea/coffee, sandwich



- Put a M&S pie in the oven using one hand
- Walk without a stick I can do this holding on to my carer around the house.

The goals were set at the right level – very stimulating.

They kept at it until I'd done them.

He wanted to charge ahead and they reined him in and in retrospect this was correct.

Asked to give goals from immediate – revised in discussion

Had goals set but within 3/52 were signed off – felt uncomfortable about this. In hindsight has other issues which should have been addressed.

Good to get tick off when achieved

They marked progress

Patient directed and focussed on what was important to them

Not everyone had a paper copy

ESD team helped to make shorter term goals for patients in order to continue working towards longer term goals

Very patient physio to help patient achieve their goals –really took on board what was important to patient. Encouraged to make a cup of tea but couldn't go anywhere with it.

Goals were set while in hospital. The OT visited after the family meeting at 4 weeks to assess the house and advised the Carer to be there for the whole of the first week.

Helped motivation of patient

Important to have copies of goals and tasks so can reflect on how patient has changed/improved

Felt well involved in goal setting process and rehab process

Felt as a carer could help give permission and direct with the goals.

Some goals felt unrealistic/unachievable

About right timescale for goalsetting

Had paper copies of goals to reflect and look back on.

I've achieved my goals – I've got one more – I want to get back driving.

Husband and carer works as a team but important to be reassured

My goals were always much more then. They were all 'big' to me. It kept my pecker up and gave me focus. Not progressing is a huge step back, the smallest steps all



helped for me to know I was getting better, the goals did this. I set my own goals. Goals were discussed and mutually agreed. Trying to achieve too much, relying on goals, can make you frustrated. I tried to do all the exercises people told me and this has been an advantage to help me feel positive.

I got rid of my stick quickly – I decided I didn't need it (had confidence to stop).

I was asked what I wanted to achieve. I wanted to go for a walk and mow the lawn.

I was part of the goal decision. They asked me what I thought I could do.

I was involved in goal setting.

When I made unrealistic goals they suggested a first step, then do that next.

I was quite happy with goals from speech therapy. There were things I didn't think I would ever do but they got me there.

My last goal was to walk just with a stick. I had 2 or 3 attempts but I was wobbly. I don't do it anymore. It's more difficult on my own.

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

Warning that service coming to an end was handled well. Asked questions about emotions and wanting to end life. Felt this was completely inappropriate.

No on explained some of the sensations – GP not helping

Not totally clear on support that will be provided at home. Some lack of clarity over details.

They had a family meeting and covered most of what the carer felt it should – it was attended by the OT, Physio, nurse. Carer found it helpful and appreciated that it was held in a nice room and was a relaxed meeting. The Physio and Nurses discussed key questions with the patient and carer about the patient coping on their own at night with toileting and medication before discharge.

A leaflet was given before discharge but cannot remember being told about ESD – the rationale for it or details of the scheme.

The family meeting was key to this – it gave two weeks' notice for carers to be put into place and the care plan to be established.

Interesting to hear from different people/carers with experience of stroke.

Talk in Musgrove about stroke was very useful

There is an enormity of what you are being told, but I didn't want to hear it as I didn't want to accept it. Once over the initial shock I was more able to understand.



I had ESD explained to me.

EDS was not explained to me until it was time to go home – I didn't know what it was.

ESD – funny term – even my GP laughed.

I had ESD for 10 – 12 weeks then they came back once a fortnight.

I didn't notice the change from ESD to community team

I received a booklet at the beginning – my daughter advised me to read it.

Musgrove gave a half hour talk. There was so much information, it was really useful. It gave me knowledge about what could happen and signs to look out for. Loads of information.

Views from carers

I felt our relationship was changed and appreciated the 'third party'

I felt my needs were addressed and asked questions at the beginning about how I was coping. I thought it was too early and should be revisited later.

I saw that when patient on her own she was low on mood. – felt that some of the goals were too ambitious.

Need some acknowledgement of involvement and needs of carers – how are you?

Need someone to talk to and pour heart out to away from the person with the stroke.

Offers of help from neighbours and friends to be able to have a break.

Needed to know more about what the person was going to be like when they were discharged – information would have helped relieve anxiety

Needed to be more involved in hospital to prepare for life after discharge – see how he got from bed to commode etc. – show me ways to do things.

Could have been more opportunities to speak to ESD team as a carer. (Others felt there were the opportunities.)

Important to have family available to take strain off

Mental exhaustion, being a carer, so family supporting to take strain off is important

At the start is was very difficult to leave patient by them self, but gradually this improved

Very important to have support network



He was in for 12 weeks. The family were involved in a meeting at four weeks – it did include discussion of discharge but we did not feel any pressure from the staff about discharge.

We were trained by the Physio in the exercises to do with the patient.

There was no one focus or person to go to if there was a problem, I just got on with it.

There has been a reversal of roles which has been challenging.

He had a lot of pain in his back. As his carer I was told how much physio to do and how to tell when he was in pain. This was helpful as I could encourage him with confidence – otherwise I wouldn't have pushed him to do it – I would have been too nervous.

The carer feels has to stay strong to encourage.

Family very included and supported

Family / friends were included in supporting and encouraging rehab and progress.

Stroke really makes carers think of mortality

They talked to me as a carer to go through things – it worked well. I felt supported.

They spoke to me independently. They were concerned for me, if it was all too much, they don't want me to be ill.

How could the service be improved?

Somerset carers – sometimes clashed between visits and OT's. Better if Somerset care following care plan appropriately.

Joined up pathway— thinks the follow up after ESD is fantastic.- can't see how it could been improved.

Feels that having the role of the Somerset Care carers being undertaken as part of ESD would be beneficial to prevent duplication and poor communication

Stroke education for carers – not enough to carry on exercises and therapy programme.

More education and preparation of expectation of stroke.

Felt patient needed a couple of days to get used to being at home but carer disagrees.

It was too much. I couldn't take it all in. I felt disorientated, my house was disorganised. I could have done with one or two days to calm down and reorientate. I



understand that time is of the essence but it took about a fortnight to get used to it – people coming at different times of day – no time to eat and no rest. I had a whirring brain and I couldn't switch off.

In hospital for four and a half days. There was someone every hour asking me my name and age.

When it came to leaving hospital two people came - OT's – came in a matter of days and asked the same questions – name – age. It was the same assessment over again – tedious. I got the impression they were ticking boxes. They gave me images of animals. I understand that this is necessary for some people but it was not for me.

I had a letter explaining I'd cancelled an appointment – this was inaccurate as I had other appointments that clashed.

The list on what was going to happen given to my family and not me. It made me burst into tears as I felt my independence was taken away.

I didn't need the Somerset Care carers as I could wash myself

I couldn't plan a week ahead as I have to fit in with appointments – so I'm waiting on them to make their next appointments so I can work around them

I use a trolley in the house to move things around from room to room. They didn't give me this I had to get it/

Not repeating assessments when not necessary to me. Different departments don't share info so all do the same tests.

It would have benefited me more if they waited two days after I'd gone home. I was preoccupied with furniture and food.

There is a big gap between the knowledge of the Stroke Service and the GP

More attention to emotional andeffects on partner. Patient felt he was going through ESD well but wife had to give up significant aspects of her own life and had a significant effect on her. This is essential for the success of the patient. Can't fault my side of it.

Feels that needs of carer need to be taken into account. Continuity of people coming – it got a little bit out of shape at times. Wanted to see same person- got down to business straight away.

Takes time to make adjustments to get use to new situation. Felt was given that time eventually as long as he understood (aphasia) and wife could join in. Wife included enough in sessions. Felt wife was looked after enough.

Caring for carers is very important – it's not just exercises but understanding what's being achieved but in context to situation.

There is a difference between what ESD can do and what the GP can do – GP didn't really understand but the ESD service do but can't help as they're not GP's.



Assisting patients to have baths

Better prep for carer prior to patient leaving hospital

Involving carer more whilst patient in hospital

Would have appreciated more warning for appointments but realised that this may be difficult for the team

With lots of people (ESD and care) coming into the house, house no longer felt your own. Loss of privacy.

Lots of equipment caused disruption to house

There were problems getting some of the equipment his wife needed eg catheter and leg bags. There was a problem with the commode that was supplied and a delay in getting a replacement one. He expected more support from the District nurses and found that the GP was not proactive in prescribing medication. He felt the handover needed to be clearer about the patient's needs and expectations of the carer.

There was very little notice of discharge for the family at Taunton Hospital – one day. It was assumed the patient would be going to his home. The family had concern for his safety- felt he couldn't gook for himself or take medication without support – he couldn't use the phone to contact them if needed. For this family the key issue was limited involvement in discharge discussion.

Setting up the carer plan took several days

Provision of care by Somerset Care was the weak link. There were problems contacting the supervisor.

There has not been a key worker allocated. They are applying for continuing healthcare – it is taking a long time – several months. His view is the key worker needs to have an input to the application – Somerset County Council have told him that they don't have key workers.

The carers lacked training in the use of the particular turning equipment the patient had been given. There was also a problem with the catheter and the district nurses did not resolve the problem with the catheter. The care company had to get a second person to lift his wife – it took four hours for the problem with the catheter to be resolved.

Felt that sometimes too many different therapy staff (RAS and therapists) which felt was 'starting again' each time each therapist came

Sometimes felt tasks at home with therapists were unsettling

Would have liked to have spoken to someone without husband there.

Frustrating at times that consultant can't give definite answer on improvements and when improvement will plateau



Feel sessions where they can meet with other carers of stroke patients would be 'imperative'

Felt therapy cut-off was a bit abrupt. Graded process of dropping off therapy would be beneficial, as abrupt

Sometimes felt level of intensity four or five times per weeks could be a bit 'invading' and effects social life. Appreciates that different people could need different levels of input.

Would like to have had a session to meet other carers sooner, was important to know other people in some situation

More information on sitting services/day centres and resources available for carer relief/respite

Caregiver strain index, feel getting stressed without knowing, feel sometimes sessions are very focused on patient.

My doctor only saw me once and wasn't guite up to speed.

GP training

Government put more money in NHS so people can see you more often and for longer after coming out of hospital, including the GP.

Someone like a doctor to see me

More psychological and social support and company, someone to talk to on a down day, some human contact

Didn't know who to go to for help initially (didn't need it but didn't know).

What would be good is a set of exercises / programme that is specific for me to do when they aren't there.

I've put weight on and I don't like it. I would like to walk more and lose weight.

When lots of people are coming into the house – the carers get you up, the PT's – 5 people in one day – it's very tiring – I needed a nap.

I don't think ESD team and carers communicate – they come at all different times. ESD are punctual, carers visits are unpredictable.

When ESD stopped there was no community support.

The care agencies don't keep to time.

There could have been more advice on where we could get ongoing care and extra care.

Contact numbers for the stroke clubs would be useful.

Be aware of how tired the patient can be.



Not used to having people in the house – invading my space. But it's a necessary trade-off for the improvements you make.

Better if ESD and care providers coordinated times, or did the care in a therapeutic way which helps you learn how to do it yourself. So less people would need to come.

GP's need to more aware of ESD.

The impact of stroke

If I could drive I would go to the stroke club but I don't like to ask for lifts, then people have to wait for me. This is a barrier of access

Reading has been a big issue for husband had occipital stroke. Has difficulty/frustrations with reading and retaining of information after a stroke.

Husband felt 'rug had been pulled under him'. Husband has numbness and some difficulty with remembering things.

Stubbornness is important

Fatigue. I was so tired after doing something at home.

I'm always tired – if I sit quietly I go to sleep.

I can still write but there are lots of words I can't write. I use a dictionary – I don't understand how I can read but not write it – it's frustrating – the silliest word and I can't get it.

I was a fit person before so it was hard to understand why this happened to me.

I've never slept in the day before but I do now, sat in the chair. I was told not to over stretch myself, that I need rest.

Comments on hospital stay.

In South Petherton they made me get dressed – make up – hair done - insisted I wasn't in my night things –

I was made to choose my clothes – in Williton – I was made to put my make up on – useful practice – exercise – learning to do things left handed -

In hospital I enjoyed meeting others in the dining room and talking about progress – made good friends – when at home I missed the company but we still speak on the phone

The food in hospital is very good – nutritious and nice to look at.



Good emotional support in hospital. There is always someone to listen – they were very patient, not showing frustration. I was very bad tempered because I couldn't get my words out.

I was speaking Italian. They found an Italian nurse who came to me and told me to speak English – and it clicked and I returned to English. (Musgrove)

Physio Therapy hit and miss in hospital. They wanted me to get out of bed but I was incapable.

I didn't have physio every day, so I had intensive exercise one day and none for a few days – this was inconsistent.

I felt privileged to have a room on my own

I felt it was ironic that they would give me sweet deserts and then ask to check my blood sugar.

In hindsight the two weeks in YDH was useless. Walked in. Second stroke – onto Stroke ward. Once got to South Petherton no complaints re service/care

The transfer from Taunton to Williton was a nightmare. He said he felt he had confidence in the staff competence at the specialist unit. Visiting times at Williton were restrictive – the doors were locked until visiting time. This meant the visitors formed relationships with each other and had knowledge of their respective patients which they used to support one particular patient when it was needed on the ward.

Feels SPM was an uplifting step towards home.

SPM a calm place and felt it helped with transition from home

SPM like a 'Travel Lodge'

I only got physiotherapy three times a weeks. I would have liked it every day but not up to it every day. In hindsight you get institutional – push a button and a nurse comes.

I looked forward to meeting different people at lunchtime or by walking around the ward. I missed the social contacts at home (someone different to the nurse).

I enjoyed the food a Musgrove (x 2)

The only thing I did in hospital was to make a cup of tea.