

The Shrewsbury and  
Telford Hospital



NHS Trust

# **Carer's Survey – Learning disabilities**

## **Report**

**August - October 2018**

## 1. Background and Methodology

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The survey was carried out to assess whether carers feel adequately informed and supported by the Trust.

The survey was originally sent to 93 patients with a learning disability, who attended SaTH during November or December 2017. A second sending of the survey went to 100 patients who attending SaTH during the months of January to March 2018. The third, most recent survey was sent to 100 patients who attended during August to October 2018.

Along with the survey, each patient was sent a letter explaining that the survey was to be completed by the person who looks after them (carer or relative) and asked for them to pass on the survey to their carer for completion. Freepost envelopes were enclosed for return.

Of the 100 surveys that were sent to Aug-Oct18 patients, 19 were completed and returned, giving a response rate of 19%.

Returned surveys were scanned and verified using the Teleform scanning software; and results analysed in MS Excel.

## 2. Results

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1. Does the person you care for have a Patient Passport or "This is Me" Document?

	<b>Nov-Dec17 N=26</b>	<b>Jan-Mar18 N=31</b>	<b>Aug-Oct18 N = 19</b>
Yes	18 (69.2%)	21 (67.7%)	9 (47.4%)
No	8 (30.8%)	10 (32.3%)	10 (52.6%)
No response			

2. Were you asked to bring it with you?

	<b>Nov-Dec17 N=26</b>	<b>Jan-Mar18 N=31</b>	<b>Aug-Oct18 N = 17</b>
Yes	5 (20.8%)	9 (31%)	4 (23.5%)
No	19 (79.2%)	20 (69%)	13 (76.5%)
No response	2	2	2

3. Was the information shared with the Ward Team?

	<b>Nov-Dec17 N=26</b>	<b>Jan-Mar18 N=31</b>	<b>Aug-Oct18 N = 13</b>
Yes	14 (56%)	13 (46.4%)	9 (69.2%)
No	11 (44%)	15 (53.6%)	4 (30.8%)
No response	1	3	6

4. Do you think the information in the Patient Passport is useful to staff?

	Nov-Dec17 N=26	Jan-Mar18 N=31	Aug-Oct18 N = 13
Yes	19 (95%)	23 (95.8%)	12 (92.3%)
No	1 (5%)	1 (4.2%)	1 (7.7%)
No response	6	7	6

5. When the person you care for was admitted to hospital, were you given enough information about their treatment?

	Nov-Dec17 N=26	Jan-Mar18 N=31	Aug-Oct18 N = 19
Yes, the right amount	22 (84.6%)	23 (74.2%)	12 (63.2%)
Yes, but too much*	1 (3.8%)	0	0
No, I didn't get any info*	2 (7.7%)	3 (9.7%)	2 (10.5%)
No, I got some info, but not enough*	1 (3.8%)	5 (16.1%)	5 (26.3%)

6. If you ticked a box with a \* in Q5 please can you say why:

The staff on one ward is not aware there is more than two epileptic fits. I was not helped when she was sitting being told by staff nurse they were not seizure but she was probably excited or frustrated. I have looked after my daughter for 31 years and now what I am talking about they did not get a doctor before hitting her head on top of bed, or no meds to help with her seizures this nurse only met ? once but new more about her than me, staff left ? when stopped fitting. Bed wet from trolley falling on it and all over the floor no one was coming to help with changing bed when I ? throw them into pass in the ward they were very uncaring 2 patients who upset with the way we were treated. I feel we are wasting their time going in. Upset mum
My experience is that I have to approach staff to discuss my daughters learning difficulties - I am never approached.
We didn't see the passport.
NHS staff would not give home carer any info.
I were informed he would have an ultra sound - never happened, if it had been they would of diagnosed constipation which was exaggerated by bleeding piles. (I diagnosed prior to his discharge.) I explained numerous times J has no sense of pain this was ignored - overlooked the medical reason which may of caused the psychotic episode extremely agitated caused by piles he thought being invaded by wasps!!

7. Did you have the opportunity to talk to staff about the ability of the person you care for to: (Carers could tick ALL that apply)

	Nov-Dec17 N=26	Jan-Mar18 N=31	Aug-Oct18 N = 13
Feed themselves	9 (34.6%)	15 (68.2%)	9 (69.2%)
Drink	9 (42.3%)	11 (50%)	8 (61.5%)
Use the toilet	11 (42.3%)	12 (54.5%)	8 (61.5%)
Wash/keep themselves clean	9 (34.6%)	15 (68.2%)	8 (61.5%)
Communicate (sight, hearing, understanding info, speaking)	18 (69.2%)	20 (90.9%)	10 (77.0%)
Call for help (i.e. button pressing)	8 (30.8%)	17 (77.3%)	8 (61.5%)

**NOTE:** There was no "not applicable" option on this question; therefore, some areas may have lower percentages, due to there being no need for the patient to have help in this aspect of daily living.

8. Were there any particular difficulties concerning the person you care for that you did not have the opportunity to advise or discuss with staff?

	<b>Nov-Dec17 N=26</b>	<b>Jan-Mar18 N=31</b>	<b>Aug-Oct18 N = 17</b>
Yes	14 (56%)	10 (33.3%)	5 (29.4%)
No	11 (44%)	20 (66.7%)	12 (70.6%)
No response	1	1	2

9. If you answered yes, what were these difficulties?

When admitted patient passport was handed to ward staff they said it had be read and gave back to me but I feel shift changes on ward did not bother to read patient passport as I had it on me and they never requested it.
Do not offer help with changing bed or getting water to wash her with when I ask it always in a minute and it never comes. It's very difficult when you're on your own.
Never asked about her communication strengths - or what level her comprehension is.
Had a 5 min chat with a nurse about my son (about not understanding what a doctor may be telling him) got told he was 20 years of age although he has dyspraxia.
Weren't listening when she needed help to go toilet.
Staff had no idea how to manage J I were with him thank goodness if I hadn't of been due to his anxiety levels (caused by piles) there would of probably sedated him again. It was announced to J that he would be staying night, rather than informing us first, doctor had implied he could after tests which he never had. He was in A&E from approx. 10:45 - 9pm his needs weren't medical he was psychotic.

10. Do you feel the plans for discharge were discussed with you?

	<b>Nov-Dec17 N=26</b>	<b>Jan-Mar18 N=31</b>	<b>Aug-Oct18 N = 18</b>
Yes, completely	17 (68%)	16 (53.3%)	7 (38.9%)
Yes, a bit	5 (20%)	5 (16.7%)	6 (33.3%)
No, but I would have liked them to have been	2 (8%)	7 (23.3%)	3 (16.7%)
No, but it was not necessary	1 (4%)	2 (6.7%)	2 (11.1%)
No response	1	1	1

11. At what point were you involved in plans for the person you care for being discharged from hospital?

	<b>Nov-Dec17 N=26</b>	<b>Jan-Mar18 N=31</b>	<b>Aug-Oct18 N = 16</b>
Before they were admitted	5 (21.7%)	3 (11.5%)	0
On the day they were admitted	7 (30.4%)	4 (15.4%)	0
During their hospital stay	1 (4.3%)	9 (34.6%)	6 (37.5%)
On the day they were discharged	10 (43.5%)	10 (38.5%)	10 (62.5%)
No response	3	5	3

12. Have you heard about the carer's passport?

	<b>Nov-Dec17 N=26</b>	<b>Jan-Mar18 N=31</b>	<b>Aug-Oct18 N = 17</b>
Yes	12 (46.2%)	14 (45.2%)	5 (29.4%)
No	14 (53.8%)	17 (54.8%)	12 (70.6%)
No response	0		2

13. Have you been given a carer's passport?

	<b>Nov-Dec17 N=26</b>	<b>Jan-Mar18 N=31</b>	<b>Aug-Oct18 N = 18</b>
Yes	8 (32%)	7 (24.1%)	4 (22.2%)
No	17 (68%)	22 (75.9%)	14 (77.8%)
No response	1	2	1

14. Were you advised that you could visit the hospital at any time?

	<b>Nov-Dec17 N=26</b>	<b>Jan-Mar18 N=31</b>	<b>Aug-Oct18 N = 17</b>
Yes	13 (52%)	14 (50%)	9 (52.9%)
No	12 (48%)	14 (50%)	8 (47.1%)
No response	1	3	2

### 3. Conclusions

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Compared to previous results, the most recent survey showed a slightly lower percentage of patients reporting that the person they care for has a Patient Passport or "This is Me" document and that they were asked to bring it with them when coming into hospital. There was however an increase of over 20%, since the last survey, in the proportion of carers who reported that this information was shared with the ward team.

All three months surveyed showed that over 90% of carers felt that the Patient Passport is useful to staff. There was a slight decline in the percentage of carers who felt they received the "right amount" of information about the person they care when they were admitted to hospital, compared to previous surveys.

There was an improvement in the proportion of carers who felt that if they had difficulties concerning the person they care for, they did have the opportunity to discuss them with staff. Recent results indicated that there was a slight increase in the proportion of patients who felt plans for discharge were discussed with them, compared to the previous survey in March 2018.

All three surveys showed that carers' involvement in plans for discharge was mostly on the day the person they care for was due to be discharged. This did increase from 38.5% in Jan-Mar18 to 62.5% in Aug-Oct18; as there were no carers reporting that they had involvement before or on admission.

The recent survey showed that 29% of carers had heard of a carer's passport, and 22% had actually been given one. These figures were a slight decline on previous months surveyed. This survey did however see the highest rate of carers reporting that they had been advised they could visit the hospital at any time.

**Appendix; additional comment:**

"I felt compelled to write this letter as this survey only scratches the surface and does not cover the issues of a hospital stay for a special needs adult and their carer. I have been in hospital with my daughter 3 times over the last 18 months she has learning difficulties is wheelchair dependant and is totally dependent myself and husband for her everyday living and to be her voice. I have found varying levels of care and compassion for myself and ? on these stays. I hand ? Passport in as soon as I arrive on ward. I have never been asked if she has one I am always the first to mention it. She was admitted via A&E and felt the passport should be used there before admission so when booking a bed staff already know what is needed before you arrive I tried this in A&E in September as I expressed the need for a side room because of me staying her learning difficulties etc. and was told to sort it out with ward staff this made ? very anxious anxiety through the roof causing behaviour problems before we even arrived on the ward. I told staff straight away about ? passport they took it away to read then returned it to me said there was no side room available but would try to sort one I was very lucky on this occasion to receive a side room and a comfy recliner as I stay with my daughter for the entire hospital stay I do her care meds meals etc. The patient passport was returned to me and I put at the end of the bed where it should be but know one else bothered to read it on shift change. I think because I stay with her you are basically left to it only seeing staff for obs and meds etc. The two previous stays I spent a week in a visiting chair no offer of respite throughout. Staff would not be expected to work 24 hrs. a day 7 days a week but this is what I do as a carer. I have even no been offered a blanket and have gone 18 hrs. Without even a drink or 5 minutes respite I think changes need to be made carers are important by us staying we free up already busy staff. I don't think it is a lot to ask for carers to have little side room where they get 5 min respite have facilities to make a drink and eat and for the staff to sit with your loved one. I don't think it should be like this the anticipation or how it's going to be on admission for myself and daughter is awful. It should be standard that when a special needs adult is admitted and has a carer staying with them that they have a side room, comfy chair and chance to leave the ward for ten minutes to make a drink and know their loved one is being looked after and the patient passport followed."