

The Shrewsbury and
Telford Hospital



NHS Trust

Carer's Survey – Learning disabilities

Report

Jan-Mar 2018

1. Background and Methodology

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.

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 Jan-Mar18 patients, 31 were completed and returned, giving a response rate of 31%. This compared favourably to 29% of Nov-Dec17 patients who returned a completed survey.

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

2. Results

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

	Nov-Dec17 N=26	Jan-Mar18 N=31
Yes	18 (69.2%)	21 (67.7%)
No	8 (30.8%)	10 (32.3%)
No response		

2. Were you asked to bring it with you?

	Nov-Dec17 N=26	Jan-Mar18 N=31
Yes	5 (20.8%)	9 (31%)
No	19 (79.2%)	20 (69%)
No response	2	2

3. Was the information shared with the Ward Team?

	Nov-Dec17 N=26	Jan-Mar18 N=31
Yes	14 (56%)	13 (46.4%)
No	11 (44%)	15 (53.6%)
No response	1	3

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

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

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
Yes, the right amount	22 (84.6%)	23 (74.2%)
Yes, but too much*	1 (3.8%)	0
No, I didn't get any info*	2 (7.7%)	3 (9.7%)
No, I got some info, but not enough*	1 (3.8%)	5 (16.1%)

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

* has severe learning disability (Downs syndrome, severe autism) Every time * is admitted to hospital, his special needs never get taken into account.
Doctor told us what was the treatment and why.
Asked if I could stay and look after my sister because of her learning and toiletry difficulties and was refused. On visiting next day she was in a dirty mess in the bed and I had to take her to the toilet and clean her up.
I kept asking to see the doctor but he was on his rounds or elsewhere. They took off her vital medicine without asking why she was on it and when she was discharged she had fluid in her lungs and her oxygen levels were 70.
* has autism and is a resident at Woodcote Hall Care Home. On the day he was admitted to hospital he was attending a Day Centre and he collapsed. One of the staff accompanied * to hospital in order to re-assure * and inform nurses of his limited abilities. She was NOT allowed to stay with * for some reason and was upset that * was not accompanied by someone he knew.

7. Did you have the opportunity to talk to staff about the ability of the person you care for to:

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

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?

	Nov-Dec17 N=26	Jan-Mar18 N=31
Yes	14 (56%)	10 (33.3%)
No	11 (44%)	20 (66.7%)
No response	1	1

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

Partially sighted.
Unfortunately when * was admitted I was in myself as * stole carer, I was devastated that I had to leave * in the care of the hospital they assured me they could do this, THEY COULD NOT. I had to return to the hospital even though I was sick myself to find him wandering the hospital corridors with no shoes and socks, a hospital gown gaping open with a health care nurse and a security guard.
The only problem I had was I had another L/D service user who was with us and getting agitated so I had to leave and take him home back to Oswestry. The patient didn't like being left although he was in good hands with staff who waited until I got back to take bloods, in case there were problems. Patient liked the staff who were good and good natured. An all-round good experience of a hospital visit. One particular nurse from Yorkshire was very very good with patient.
* has very complex needs and the decision was made that he had open visiting for his own carers to come in to look after him due to staff problems.
Not being listened to.
No one asked about if she understood the questions or about any fears and difficulties she might have.
Nobody seemed to know why she was on a catheter. I told them to take it out - she is only slightly incontinent and padded up. It took 5 days from my asking and then it was only done because I was showering her (she was filthy) and I got the tube tangled up. A junior doctor came and I told him they had said they would take it out. He checked and then said ok and took it out.
They didn't listen.
I am * sister and NOK and live in S Wales as our 3 children live in this part of the UK. Because of this I rely heavily on the care staff at Woodcote Hall and the Day Centre. I was informed of * admission to hospital and was in touch with the Care Home, the Day Centre and hospital that day. I would have been with him if I had lived nearer and was upset that with a carer acting on my behalf was not allowed to stay.
I did have to work hard at getting information at time and be listened to ref her diabetes. She appears to understand but doesn't take anything in and generally laughs smiles and agrees with people so they still relayed to much to her directly and I had to chase sometimes.
The aftercare.

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

	Nov-Dec17 N=26	Jan-Mar18 N=31
Yes, completely	17 (68%)	16 (53.3%)
Yes, a bit	5 (20%)	5 (16.7%)
No, but I would have liked them to have been	2 (8%)	7 (23.3%)
No, but it was not necessary	1 (4%)	2 (6.7%)
No response	1	1

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

	Nov-Dec17 N=26	Jan-Mar18 N=31
Before they were admitted	5 (21.7%)	3 (11.5%)
On the day they were admitted	7 (30.4%)	4 (15.4%)
During their hospital stay	1 (4.3%)	9 (34.6%)
On the day they were discharged	10 (43.5%)	10 (38.5%)
No response	3	5

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

	Nov-Dec17 N=26	Jan-Mar18 N=31
Yes	12 (46.2%)	14 (45.2%)
No	14 (53.8%)	17 (54.8%)

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

	Nov-Dec17 N=26	Jan-Mar18 N=31
Yes	8 (32%)	7 (24.1%)
No	17 (68%)	22 (75.9%)
No response	1	2

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

	Nov-Dec17 N=26	Jan-Mar18 N=31
Yes	13 (52%)	14 (50%)
No	12 (48%)	14 (50%)
No response	1	3

3. Conclusions

Both surveys indicated that similar proportions (68-69%) of carers/relatives had a 'Patient Passport' or 'This Is Me' document for the person they care for. The most recent survey results showed a 10% increase in carers/relatives who were asked to bring it with them on admission to hospital.

It is encouraging to see that 95% of all carers in both surveys felt the Patient Passport is useful to staff, even though only half of the carers felt the information was shared with the ward team.

Jan-Mar18 results indicate a decline in the proportion of carers who felt they got enough information about the person they care for regarding their treatment.

The recent survey results show much higher proportions of carers reporting they had the opportunity to talk to staff about the ability of the person they care for.

In the Nov-Dec17 survey over half of the carers who responded (56%) felt that there were particular difficulties concerning the patient that they did not have the opportunity to advise staff of. There was however a clear improvement in the Jan-Mar18 results as this dropped by over 22%.

The proportion of carers who felt discharge plans were not discussed with them, but would have like them to have been, rose from 8% in Nov-Dec17 to 23.3% in Jan-Mar18. It's evident that there were fewer cases where discharge plan discussions were left until the actual day of discharge in Jan-Mar18 compared to in Nov-Dec17.

Approximately 54% of patients across both surveys carried out had not heard of the 'carer's passport'. The number of carers who actually received a 'carer's passport' did however rise from 68% in Nov-Dec17 to 75.9% in Jan-Mar18. Both surveys indicate around half of carers were advised they could visit hospital at any time.