

HOW DOES IT FEEL FOR me?

Kari / August 2019

COULD YOU TELL US A BIT ABOUT YOUR EXPERIENCE OF HEALTH AND CARE SERVICES IN THE LAST MONTH?

I've been in hospital again (St James), I was very poorly this time with my heart which was full of fluid. It was different this time, I have a DNR (Do Not Resuscitate) that I've had in my notes for quite a while and they put it 'active' this time and I knew something had moved on. I thought my time had come, I really did. I had to fill in a 'respect DNR form' (see overleaf) and the consultant said, "Don't you worry, I will respect your 'respect DNR' form. Just because we can't resuscitate doesn't mean there's not a lot we can do". I told him, "Well you've got a scale on your form, it needs changing, it's very black and white and not easy for your family to understand, it doesn't say a lot".

Andrew [Community Matron] was going on holiday and the agreement we had was that if I needed extra water tablets, I should go to the doctors. I got to the surgery and the doctor said, "Kari, you know where you're going", and it was 999 from the surgery. That's how it always is when Andrew's on holiday (he's not ever allowed to go on holiday again!), it shows how much his role means to me.

[when I arrived at A&E], I remember the nurse said, "You're in resus, in Casualty" and all that was going through my head was, "I'm in resus, and I'm 'Do Not Resuscitate', someone's screwed up here."

When I got to the ward (J12, respiratory), I was in the Hollywood suite, I had a room of my own with ensuite bathroom and telly, and I thought, 'they either know about Healthwatch or I'm very, very ill!' The care was brilliant.

When I was on the ward, the heart consultant told me the Heart Failure Team (an outreach team who see people in their own homes) is going to come and see you. The lady from that team, she promised me the earth I felt, I asked her a lot of questions and she answered them, and said, "this can be done and that can be done, we'll catch up with you next week", and then when I get home Andrew comes and says the Heart Failure Team aren't keeping you on because it's the right hand side of your heart, and there's nothing they can do. I felt dumped, that was cruel, they shouldn't tell you a load of stuff while you're in hospital knowing they're not even going to see you at home. Who benefits from that? I don't. Even if they came to see me to say there's really not much we can do, they could tell me about other places, there must be a voluntary organisation that can help. It's happened before, and they did it to me again - the Heart Failure Team have failed me because there's nothing they can do.

DID YOU FEEL YOU WERE LISTENED TO?

I did yeah. The whole admission and everything seemed different this time. I did wonder if it was because of the active DNR, they listened a bit longer, were extra caring and you felt it. I asked to see a pastor, and this nurse did everything she could to get me to see this pastor and she kept on until she sorted it. In that respect they were great.

DID IT FEEL 'JOINED UP'?

Yeah, this time it did. Well I've come back with a package of care haven't I?

Also, did you know they've got a discharge lounge now at St James in Lincoln Wing? It was a good four hours, but you got tea, sandwiches, telly, a comfy chair, people to chat to. I didn't mind, it made the wait bearable. They sorted your medication. The longest bit was waiting for my transport.

IF YOU COULD HAVE CHANGED ONE THING TO MAKE YOUR EXPERIENCE BETTER THIS MONTH, WHAT WOULD IT BE?

I don't know really

CAN YOU TELL US ABOUT THE CARE YOU'RE GETTING AT THE MOMENT?

Since leaving hospital this time, I'm with the Reablement Scheme (SkILs team), I'm getting five weeks free care, and they come in three times a day. After the five weeks from SkILs they pass you on to whatever care you need, but I'm going to have to pay for it. Usually, I have to pay £300 a month for 12 hours care a week out of my benefits. That's only for care four days a week, the other three I just have a quick wash with baby wipes. The consultant was saying, you need more care at home. I said I can't afford it. That's what this poem is about - I did present to hospital this time as a very smelly person.

AT WHAT COST?

"Take more care of yourself
Please take care..."
How could she do that
With little money to spare?
She could get help to shower
7 days a week
That would leave her
With very little to eat
If she cut it down to 3
With incontinence
She would indeed smell
At least it would put
More tins on the shelves
She could get help to dress
7 days a week
Or live in her night clothes
Facing more defeat
She could add an extra jumper
When her electric is low
Almost on emergency
Almost only 5 more days to go
She could end up in hospital
Taking up a much needed bed
Because they have decided

She must pay for her own CARE instead
She has worked most of her life
Not hard to understand
A smoker, self inflicted
Her illness due to her own hand
She hopes her words
Will indeed reach all
Don't be so quick
When making a judgment call
Please don't judge a person's
Poor hygiene
Why in dirty clothes are they dressed
Why they may look angry
Sad or depressed?
Those that are riddled with debt
Not always their doing
Would be a safe bet
Taking away their dignity
Would be just too much to bare
All because they didn't have
Enough money
To pay for their CARE
Her job title.....A CARER

Poem by Kari Thomason

1. Personal details

Full name

Date of birth

Date
completed

NHS/CHI/Health and care number

Address

2. Summary of relevant information for this plan (see also section 6)

Including diagnosis, communication needs (e.g. interpreter, communication aids)
and reasons for the preferences and recommendations recorded.

Details of other relevant planning documents and where to find them (e.g. Advance Decision to Refuse Treatment, Advance Care Plan). Also include known wishes about organ donation.

3. Personal preferences to guide this plan (when the person has capacity)

How would you balance the priorities for your care (you may mark along the scale, if you wish):

Prioritise sustaining life,
even at the expense
of some comfort

Prioritise comfort,
even at the expense
of sustaining life

Considering the above priorities, what is most important to you is (optional):

4. Clinical recommendations for emergency care and treatment

Focus on life-sustaining treatment
as per guidance below
clinician signature

Focus on symptom control
as per guidance below
clinician signature

Now provide clinical guidance on specific interventions that may or may not be wanted or clinically appropriate, including being taken or admitted to hospital +/- receiving life support:

CPR attempts recommended
Adult or child

clinician signature

For modified CPR
Child only, as detailed above

clinician signature

CPR attempts **NOT** recommended
Adult or child

clinician signature

5. Capacity and representation at time of completion

Does the person have sufficient capacity to participate in making the recommendations on this plan?
Yes / No

Do they have a legal proxy (e.g. welfare attorney, person with parental responsibility) who can participate on their behalf in making the recommendations? **Yes / No / Unknown**
If so, document details in emergency contact section below

6. Involvement in making this plan

The clinician(s) signing this plan is/are confirming that these recommendations have (circle at least one):

- A** been recorded after discussion involving this person, who has sufficient mental capacity to participate in making relevant decisions
- B** where appropriate, been discussed with a person holding parental responsibility
- C** in the case of a person who does not have sufficient mental capacity to participate in relevant decision-making, been made in accordance with capacity law
- D** been made without involving the patient (or best interests/overall benefit meeting if the patient lacks capacity)

If **D** has been circled, state valid reasons here. Document full explanation in the clinical record.

Date, names and roles of those involved in discussion, and where records of discussions can be found:

7. Clinicians' signatures

Designation (grade/speciality)	Clinician name	GMC/NMC/ HCPC Number	Signature	Date & time
Senior responsible clinician				

8. Emergency contacts

Role	Name	Telephone	Other details
Legal proxy/parent			
Family/friend			
GP			
Lead Consultant			
Other			

9. Confirmation of validity (e.g. for change of condition)

Review date	Designation (grade/speciality)	Clinician name	GMC/NMC/ HCPC number	Signature