

Design in Social Care Discovery Report

February 2019



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Our problem statement

How might we better prepare people to make decisions about their life and support after hospital?

Our project team

- Project Manager, Lewisham Council
- Neighbourhood Coordinator, Health and Social Care
- Age UK Lewisham and Southwark
- University Hospital Lewisham

Our approach

- We conducted in depth interviews, via home visits and telephone calls with people caring for someone who was recently discharged from hospital.
- The interviews conducted were broad discussions of the journey from hospital to community based care and where they felt information about financial contributions was received and needed.
- In all cases the person being cared for was living with dementia, and was contributing financially toward their care. Wherever possible interviews were conducted with carer and cared for person together.
- In addition we collaged survey response's from 47 professionals on financial assessment and information provision.



We journey mapped people's experiences of being in hospital...

Journey Map

Journey Home to hospo to home

User:

(Title, a sentence that describes the thing the user is trying to do.)

(Who's using the service? What defines them as your user?)

Journey Stages:

Give each stage of the journey a title and a brief description.

Before	Admission	Preparation	Discharged	Community
Admission	to	for	with	care at
	Hospital	discharge	care package	home

Storyboard:

Draw the actions or key touchpoints at each stage. Stick men are very welcome!



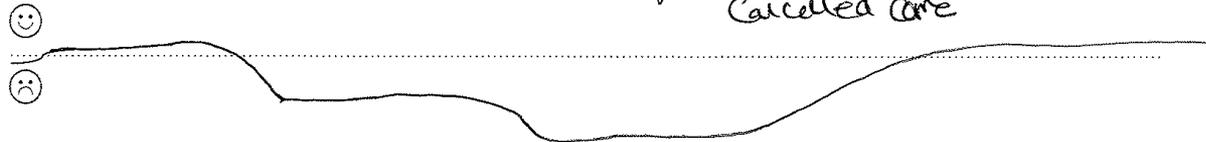
What happens

Describe the stages involved in detail. Feel free to bullet point but make sure to include any important details.

I provide my wifes care at home.	Had a fall at home so used pendant & was admitted.	Informed was medically fit but must have care package	carers came but I'd already get my wife up & dressed. Cancelled care	Now I look after my wife with support from children
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Emotional Experience:

Chart the user's emotions as they move through the stages - positive, neutral or negative.



Touchpoints:

Note down any touchpoints, e.g., phone call, website, sales person.

Husband & wife	linkline	Hospital staff	Agency carer	Husband & wife
Son supports	↓ Ambulance			son
	↓ Hospital staff			church friend - cleaning

Journey Map

Journey

User:

(Title, a sentence that describes the thing the user is trying to do.)

(Who's using the service? What defines them as your user?)

Journey

Stages:

Give each stage of the journey a title and a brief description.

Before hospital Admitted to hospital Prep. for Discharge Discharged with plan Daughter + Granddaughter care

Storyboard:

Draw the actions or key touchpoints at each stage. Stick men are very welcome!



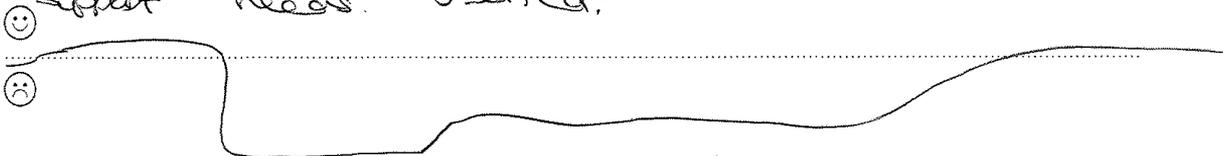
What happens

Describe the stages involved in detail. Feel free to bullet point but make sure to include any important details.

Mum was living at home & independent with my support
 Taken into hospital after fall. Hosp not meeting needs.
 Informed was Med. fit but couldn't go w/ a. plan sorted.
 I cancelled carers on lot day. I supplied
 Daughter lives with Mum & is sup by gr daughter

Emotional Experience:

Chart the user's emotions as they move through the stages - positive, negative, neutral or negative.



Touchpoints:

Note down any touchpoints, e.g., phone call, website, sales person.

family supp Hosp staff Agency carer Family only
 - lots of family involved

Journey Map

Journey:

(Title, a sentence that describes the thing the user is trying to do.)

User:

(Who's using the service? What defines them as your user?)

Journey

Stages:

Give each stage of the journey a title and a brief description.

At home not managing	Dementia diag. at home.	Hosp. admission	Prep for disch. to care home	Placed in Care Home
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Storyboard:

Draw the actions or key touchpoints at each stage. Stick men are very welcome!



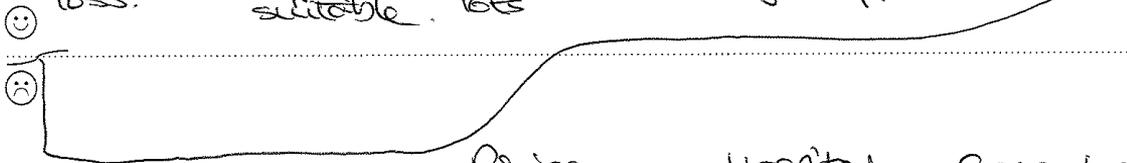
What happens

Describe the stages involved in detail. Feel free to bullet point but make sure to include any important details.

- Wandering - calling police - confused - daughter at loss.	- Daughter gets to GP → diag. - Card issues as before - sup not suitable.	- Police bring to hospital - hip break in hospital - made wards lots	- capacity assessed - decision care home - 3 weeks + daughter plan	- In care home near daughter Settled well.
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Emotional Experience:

Chart the user's emotions as they move through the stages - positive, neutral or negative.



Touchpoints:

Note down any touchpoints, e.g., phone call, website, sales person.

GP family	Memory service - GP	- Police - Hospital	- Hospital incl. spouse	Care home & family
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Journey Map

Journey

(Title, a sentence that describes the thing the user is trying to do.)

User:

(Who's using the service? What defines them as your user?)

Journey

Stages:

Give each stage of the journey a title and a brief description.

Before hospital Admission to hosp Transfer to rehab & recovery Discharge with care plan Decrease care plan & support

Storyboard:

Draw the actions or key touchpoints at each stage. Stick men are very welcome!

What happens

Describe the stages involved in detail. Feel free to bullet point but make sure to include any important details.

I live with Mum to support her use manage or any
 Wasty falls into hospital for sometime
 Discharge to rehab centre
 Discharged with 4x D care package
 Decreased to 2x per week and son does most

Emotional Experience:

Chart the user's emotions as they move through the stages - positive, neutral or negative.

Touchpoints:

Note down any touchpoints. e.g., phone call, website, sales person.

Family and GP Hospital → social worker → agency centres

Journey Map

Journey

(Title, a sentence that describes the thing the user is trying to do.)

User:

(Who's using the service? What defines them as your user?)

Journey

Stages:

Give each stage of the journey a title and a brief description.

At home & well
Admission to hospital - long stay - surgery with Benbawt support
Discharge with new small package + car
Reassessed

Storyboard:

Draw the actions or key touchpoints at each stage. Stick men are very welcome!



What happens

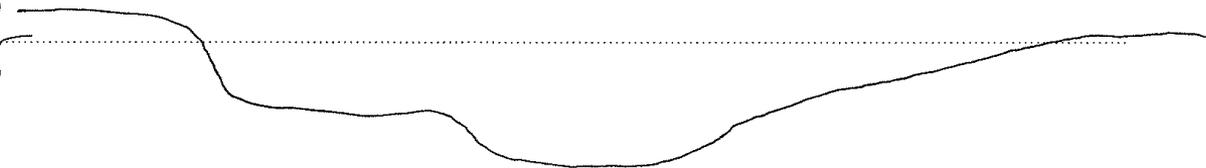
Describe the stages involved in detail. Feel free to bullet point but make sure to include any important details.

~~Bad fall~~ Bad fall, broken up
~~Broken~~ into hosp - Benbawt - husband died!
Independant home w husband
long hosp stay with enablement 1/2 hr per day
Discharged with small care package
Reassessed new

Emotional

Experience:

Chart the user's emotions as they move through the stages - positive, neutral or negative.



Touchpoints:

Note down any touchpoints. e.g., phone call, website, sales person.

various hospital

social care agency worker

care agency

Who we spoke to

We identified 5 key persona groups:

1. John (90)

Living with dementia, recently discharged from hospital, contributing financially to their care

2. Elizabeth (58)

“New carer”, no previous experience of the system but has increasing care responsibilities

3. Jessica (30)

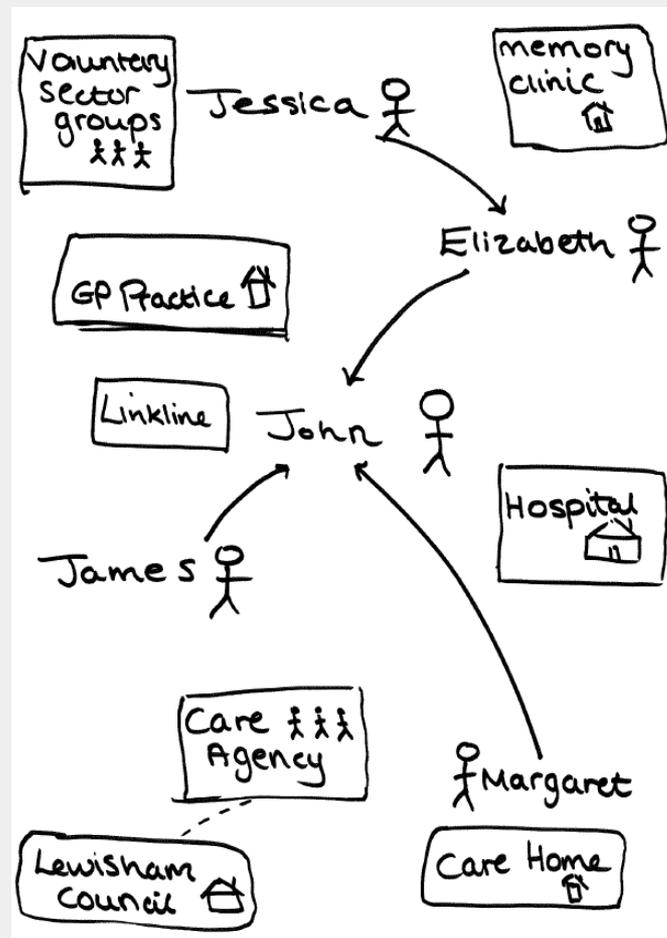
“Carers supporter” who helps when they can

4. James (42)

“experienced carer”, knew to caring for mum, but knows the system well

5. Margaret (58)

Daughter and next of kin but living quite far way



Key findings

- Most people had some understanding that they would pay for care, but people wanted information at the earliest possible point about this.
- People are confused by the discharge process.
- Carers are often not involved in plans for discharge or not kept in the loop.
- Unwanted care packages had been set up for people.
- People want things to go ‘back to normal’ after hospital and don’t want additional care unless they really need it .

“It’s a difficult time when someone is being admitted to hospital and suddenly you have more responsibility as a carer. You don’t want to be worried that a big bill might be coming. Need to be reassured that there is a way through and support available to navigate and make these decisions.”

Key findings: we found 5 emerging themes

Information to strengthen community assets

- GP is important source of information
- Want to speak to people for advice
- Information for carers is needed

Listen to the 'whole unit'

- Assessing the facts, resources and needs
- Talk about what is working
- Cared for and carer should be in control of the support they want

Family Dynamics and Money

- Disparate families
- Missing financial information
- Confusion/ anxiety around arguing families
- Managing expectations of family

Involve the carer

- Need consistent updates
- Need to be involved in key conversations and plans
- Reluctance to involve carer who doesn't have power of attorney

Confusing systems, processes and mixed expectations

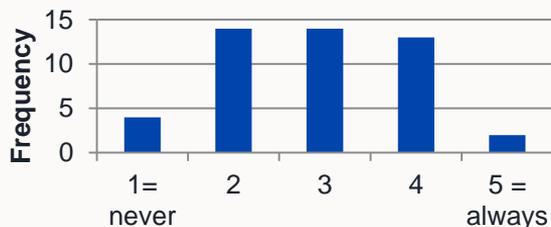
- Mixed messages from different professionals at discharge
- Professionals nervous / risk averse
- Loss of control and ownership of my decisions
- Carers don't feel trusted or understood
- Carers don't trust professionals

User needs

- **As a** person living with dementia **I need** my carers needs to be considered alongside mine when preparing for discharge from hospital **so that** we can invest in the support most relevant to us both.
- **As a** long distance care-giver **I need** to be kept in the loop and involved while my loved one is in hospital **so that** I can balance my caring responsibilities, make financial or other life plans in advance.
- **As a** new carer **I need** clear, simple and straightforward information and advice about any potential costs and the discharge process as soon as possible after admission **so that** I know what to expect and what decisions I need to make.
- **As an** experienced carer **I need** professionals to trust me to make financial and care decisions **so that** I can help my loved one return to normal after they come home from hospital.
- **As** someone who supports a carer **I need** to be remembered and considered in key decision making **so that** I can help re-establish the home routine and minimise unnecessary services.

Professional needs

How frequently clients ask about financial contributions to care



Self-rated understanding of financial assessments in Adults Social Care



- 52% of professionals felt information about the cost of care should be **given as soon as possible** and **any professional** should be able to provide this information.
- **Only 2%** felt they had a very high knowledge of the financial assessment process.
- **91%** of professionals felt the level of understanding in the **general public** was **low or very low**.

User Needs – professionals

- **As a** member of the hospital staff **I need** a basic understanding of contributions to care **so that** I can give clear and accurate information to patients about what to expect.
- **As a** social worker, **I need** to feel confident in my knowledge of paid for care and support **so that** I can give people accurate information about their options regarding care.
- **As a** health and social care or voluntary sector professional **I need** to know that people may have to contribute toward care and where to find more information **so that** I can accurately inform and signpost people I support.

“Every professional should have an understanding that there could be a potential cost. They should warn the client they may have to pay towards their care. Financial Assessment Team, will then be the ones to tell them how much they have to pay.”

What we have learned

- Tricky to engage with people without carers or advocates.
- Understanding and satisfaction was very varied
- Difficult to keep people focused on conversation
- Power of Attorney, and not having it is causing issues.
- Ideally more time to identify a wider number of people would have been good.
- People with high care needs are tricky to do interviews with – can't necessarily get access, can't get clear communication, capacity issues.
- Professionals are VERY busy, interviews weren't always feasible so moved to survey.
- Can't look for the solution before we've done the research.
- Journey's do not fit pathways. Categorising people based on their pathway for discharge doesn't work, other factors such as prior experience have a bigger impact on the journey
- People do not know which professional is which or from where.
- People have very complex needs and often very unwell so difficult to get cross section for research.
- Professionals are quick to put packages of care in place without knowing the persons 'assets'; therefore disempowering people.
- No quality support for those who take on 'caring' or support roles outside of professional paid help.