What happens to people with dementia when they move between care homes and hospitals?

A report by CQC saying what we found out

This is an EasyRead version of:

Cracks in the Pathway
People’s experiences of dementia care as they move between care homes and hospitals

October 2014
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What is dementia?

Dementia is a disease that mostly affects older people.

There are different types of dementia, but they can include problems with:

- remembering
- thinking properly
- sorting out problems
- talking with others.
It gets worse as time goes on and there is not a cure.

Each year there are more and more people who have dementia.

Nearly all the older people in English care homes have dementia or a similar difficulty.

4 out of 10 older people in hospital have dementia.

Last year CQC looked at what happens when people with dementia move between their care homes and hospital.

This EasyRead report is what we found out.
What we think

Good care helps keep people with dementia fit and well.

It stops people going into hospital so often and gets people out more quickly.

It makes people feel better about any changes, like going into hospital.

People with dementia have the right to good care that meets their needs.
One person said:

I am not always able to make decisions myself. So staff talked to my family and friends about what was best for me.

And another said:

No one listens or asks what I want. People treat me like I can’t think at all. It makes me feel like nothing.
What we looked at

We looked at the care of people with dementia in 129 care homes and 20 hospitals.

We asked people about their care and what was important to them.

One person said:

When I had pain I was not able to tell the staff.

This meant I didn’t get any help for a long time.
We know there is lots of good care. These services:

- treat people as individuals
- have well trained staff
- have time to meet people’s needs
- have good, up to date assessments and show these to others who need to know.
We all want all services to be like this. It is sad that some are not.

When we find poor care, we take action to do something about it.

We are starting to give services a score to show how good they are.

This will help them get better and give people more information to make better choices.

We heard from lots of people with dementia about their care. What they said made us certain we need to change and we hope others will change too.
What we found out

We found more good care than poor care.

But the care people got varied.

This means that most people with dementia will have poor care at some time.

This needs to change. People with dementia have the right to be treated with:

- respect
- dignity
- kindness.
We will do what we can to make sure this happens.

There have been guides about how people with dementia should be treated for years, but much more needs to be done.

9 out of 10 places had some poor care.

These were the areas of care with problems.
Checking what people need (assessments)

Services did not always look at people’s needs. They did not always think about how dementia affects a person.

They did not always say which staff would help them.

Hospitals thought more about people being physically sick and not their other needs.

Services did not always find out how much pain people were in.

Nearly 1 in 3 care homes and over half of hospitals had problems.
Planning to meet people’s needs

Services did not always follow the guides for good care.

They missed changes in people which meant they didn’t get the right care.

Putting people at the centre of their own care helped.

Not checking for the problems that we know people with dementia are more likely to have meant more stays in hospital.
Moving to different places or having different staff often caused problems for people with dementia.

Giving people privacy and treating them with respect was important.

One person said:

I was able to find my own room because it had a blue door, and pictures on the door helped me find the bathroom.

1 in 3 care homes and 2 in 5 hospitals had problems.
Services working together

Care homes and hospitals did not always give each other the information they needed.

This meant people’s needs were missed.

People with dementia need support from a range of professionals, who need to know about the person to help them properly.

Staff should give people more information about others who could help.

One person said:

In hospital they lost my ‘This is Me’ book when I moved to another ward. Staff did not know or ask about my dementia.

Over 1 in 4 care homes and more than 2 out of 10 hospitals had problems.
Staff knowing about dementia

There were not always enough well trained staff to care for people with dementia.

Not all staff knew what good care looked like for people with dementia.

They just did their jobs and did not think about how people felt.

Training was not checked to see if it did any good.

People said being treated with care and kindness by staff who understood their needs was the most important thing.

One person said:

I ate what was given to me. But sometimes I saw people eating other food that I would have liked instead.

Nearly 1 in 3 care homes and over half of hospitals had problems.
Including families and carers

People were not always involved in the care from their service.

Good care involves family, friends and carers in decisions and choices about care.

1 in 3 care homes and 3 out of 5 hospitals had problems.

Services checking how good their care was

Services did not always check how good their care for people with dementia was.

So they did not know how to get better.

Nearly 2 in 5 and nearly 1 in 3 hospitals had problems.
What will CQC do now?

We will:

- have a new national person helping services give better care for people with dementia

- give our inspectors better training about what good dementia care looks like

- have a part in our reports on hospitals that says how good dementia care is.
Where to go for more help

CQC Website:
www.cqc.org.uk

The Alzheimer’s Society:
www.alzheimers.org.uk

Dementia Action Alliance:
www.dementiacaoaction.org.uk

Skills for Care:
www.skillsforcare.com
Skills for Health:
www.skillsforhealth.org.uk

Healthwatch England:
www.healthwatch.co.uk

NHS Choices:
www.nhs.uk

Social Care Institute for Excellence – Dementia Gateway:
www.scie.org.uk/dementiagateway
How to contact CQC

Telephone our Customer Care Team on:

03000 616161

Email:

enquiries@cqc.org.uk

Write to:

CQC
Citygate
Gallowgate
Newcastle upon Tyne
NE1 4PA

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ISL 148/14
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