“Good support isn’t just about ‘services’ – it’s about having a life.”

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IMPACT Network – supporting older people coming out of hospital.

Discussion material for local Network session 1

Easy read version

Who is this for?

This leaflet has information for our **Local Network session one**.

Before our first session, we’d like everyone to **read this leaflet**. This leaflet is an introduction to the issue we’re going to explore over the **next six months.**

That issue is **Supporting older people coming out of hospital.**

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This leaflet includes different **research** and people's **lived experience** around this issue.

We want to discuss what reasons may **stop older people** from having the right support **when leaving hospital.**

We want to make sure that people **don't feel blamed** when they are in hospital.

We also want to look at the problems in how the **hospital and social care** systems **work together**.

What is the issue?

Hospital discharge is a **really difficult** area of policy and practice for lots of reasons.

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For **older people** especially, things can get complicated **with arranging social care** after they leave hospital.

Sometimes someone is **ready to leave** hospital, but they **have to stay in** hospital because of a **lack of support** when they get home.

This is sometimes called a **delayed discharge.**

This is a problem that has been **going on for a while**, with lots of the same issues coming up again and again.

In the UK the first government guidance on this issue was **published in 1963.** There were delays that go back to the very **beginning of the NHS** and before.

This is also an **international issue**. This means it is affecting lots of different health and social care systems **around the world.**

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The research shows that there are **lots of problems** around health and social care teams **working with each** other to provide support.

Some of this is because of **communication between teams**. Other times it’s because the **rules and ways of solving problems** that these teams follow are different.

There are also risks when **sending someone home too early**. It can be just as harmful when there isn’t the proper **support in place**.

We think that there needs to be **big changes in the system**. We think more needs to be done to see things through the eyes of the **older person in hospital.**

We need to focus on what matters to **them and their families** the most. We need to understand how **frustrating** this can be.

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Avoiding negative and harmful language

Before exploring these issues further, it is important to talk about **the language** we use when talking about **older people in hospital.**

This issue is something that is reported on in **news quite a lot**. But the language used can often be **very harmful.**

Historically, people have used the term **bed blocking**. They also described the people stuck in hospital as **bed blockers.**

This is still the case in the **media** and sometimes from **health professionals.**

These stories make headlines talking about how **this affects hospitals**, but not about how it affects **people and their families.**

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Most people see **bed blocking** as an **offensive and unhelpful term**. They feel like it is blaming the victim.

Sometimes the person is **treated like it’s their fault they are still in hospital.** But that person is likely desperate to get home and is only there because the system can’t **organise itself to get them out.**

A more neutral term is **hospital discharge** or **delayed discharge.**

But, the use of the word **discharge has a risk** of making hospitals think **their role is finished** when the person leaves.

It can make hospitals think they don’t have a role in **helping people transition** out of hospital.

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A better way to describe this situation could be **delayed transfer of care.** This helps explain what is taking a while to set up and keeps all teams involved in the **transfer of care.**

The problem with this is that longer phrases **often get shortened**. We don't think many people wouldn't understand what DTOCs stands for or how **helpful it would be.**

For the rest of this leaflet, **we will not use the shortened version** but call these situations **delayed transfers of care**.

What is the impact on health services?

A lot of focus in the NHS currently is around **tackling long waiting lists** and rebooking cancelled appointments that were caused during COVID.

Freeing up beds by **solving delayed transfers of care** is a big part of getting these waiting lists back under control.

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Keeping someone in hospital is **expensive**. There are also lots of times when people’s **need for beds** is higher than the beds available.

Because of this, there is a lot of **pressure on healthcare staff** to not have people in beds that don’t need them.

The **delays in people leaving hospital** when they are ready to go home is **frustrating for a lot of staff.**

But sometimes those **frustrations between health and social care** working together can become one-sided towards hospital staff.

This is where the impact on our very strained NHS service is seen as **most important**, ignoring how important **social care can be for older people**.

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But even though **waiting for social care** can cause big delays, it actually causes **less than half** all delays in transfers of care.

Before the **COVID 19 pandemic**, for example, social care was the reason for about 40% of delays. While this is a lot, the **NHS was responsible for the other 60%.**

A lot of this is to do with **money**. Supporting older people to leave hospital is **only a small amount** of what adult social care spends its money on.

What is the impact on older people and their families?

While delays leaving hospital have a **big impact on the NHS**, they have just as big an impact on **patients and families.**

Hospitals are **busy and noisy places.** Most people want to get home as **quickly as they can**.

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Staying in hospital for **longer than you need** can also put you at risk of picking up an **infection from the hospital**, like MRSA.

Being in a **hospital bed all day** can also reduce people’s independence and **ability to do different things**.

People with learning disabilities or with dementia often find hospital **really confusing.** This can lead to further issues, which make **keeping their independence even harder.**

There are lots of other factors that **delay transfer of care**. Below are some of the issues that have been going on for a long time.

They are:

- **bad communication** between hospital and community services.

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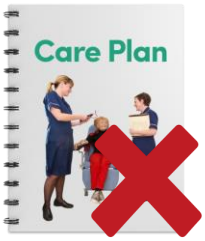
• **Bad planning** when people need more support after they leave hospital.

• **Not telling people** or their families when they are being discharged, and this sometimes **happens very quickly.**

• Relying on **unpaid carers** when people are discharged, especially when their **needs have changed.**



• Not setting up the **right support** for someone when they leave hospital, or this process being **very slow**.

• Not thinking about groups of people who might need **even more support**. This may be people with **dementia** or **homeless people**.

There have been some **research studies** that talked to older people and to families about how being in a **delayed transfer of care feels.**

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They said it was **very upsetting**. People describe being at their **wit's end** and feeling **completely helpless.**

They say it feels like they have **no say in what happens to them**. Their families feel completely taken for granted and **left without the right support.**

Negative experiences of hospital discharge

This section has some examples from **Age UK's advice line**. These are real people's stories with their names and some **details changed to protect their identities.**

If you would like to read more people's stories, please **let our team know**.

Mary and Paul's Story

Meet **Mary and her Husband Paul**. Mary is **85 years old and is currently in hospital.**

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Paul rang Age UK's **advice line** for help with their situation.

Mary has **lost her mobility** during her time at the hospital.

Yesterday the hospital told Paul that **Mary was ready for discharge** today. They told him she can't stay in the hospital anymore.

Paul is confused because nobody has come to see what she will need **to help her recover at home.**

There hasn't been any talk about if Mary can get her mobility back. No one has talked about what **adaptations they need** at home.

Paul was able to delay Mary's discharge for a day by getting the **Patient Advice and Liaison Service involved.** They are also known as **PALS.**

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Paul wasn't given any **information about Mary's rights,** or about how they are going to manage at home.

Rachel and Janet's story

Meet **Rachel and Janet**. Janet is Rachel's daughter. She rang the Age Uk advice line. Her mother Rachel is in **hospital for the second time in 10 days**.

Rachel lives in her own home, but Janet doesn't feel like **she is safe at home currently**. Janet feels she **shouldn't have been discharged home** before and is going to complain.

Before Rachel went back into the hospital, **the Intermediate Care Team** agreed that **she wasn't safe at home**.

Now that Rachel is back in hospital **Janet is worried** that the same thing will happen again.

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Janet doesn’t know what the **responsibilities of the hospital social worker** are and who, if anyone, **links all the assessments up.**

What’s the big picture?

Some of the biggest issues **aren’t just about delays in leaving hospital**. There are lots of challenges and problems that mean people have **bad experiences.**

There can be big problems with **sending someone home too early** from hospital as well.

This is called **premature discharge** which is when **someone feels pressured to leave the hospital** before they feel ready to go home.

Hospital discharges cause problems when they **are badly organised.** There should be more focus on **working as a whole team** to help someone.

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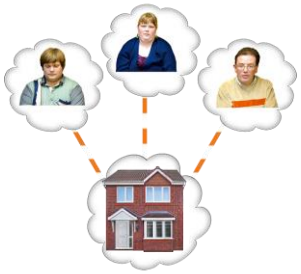

When **pressures increase on hospitals**, staff feel like they have to send people home at almost any cost.

This can lead to people being **sent to care homes**, rather than taking the time to help people **return to their own homes.**

There is a big risk that short-term **care home stays will turn into permanent ones**. The main reasons for this are understaffing and lack of access to things to help people recover.

This can lead to people being told they are **unable to be at home safely** far earlier in their lives than what is necessary.

Lots of people would argue that **no one** should be admitted straight to a care home from hospital unless **that is where they were living before.**

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Hospitals are a really bad place to **make important and long-term** decisions about someone’s future. They might be **scared, in pain, disorientated and not themselves.**

People are usually **desperate to get home from hospital**. They want to recover with support somewhere they know best **before making any big decisions.**

There has been efforts in the past to **create new services** that people can go to for additional support after hospital.

But these services **can quickly fill up**, becoming just as blocked as the **hospital beds they were made to free up.**

There are some fantastic **services that provide personalised care and support**. They have been reported **to build people’s confidence** and help them return home.

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But there’s also a danger that even if these services **work for some people**, it is not solving the **problems in hospitals**.

We are also **not involving older people** and families in designing services enough.

While all the policy focus tends to be on **discharging people from hospital**, it’s just as important to **help people stay as healthy and independent as possible**.

The Audit Commission pointed out a **vicious cycle** where there isn’t enough to prevent people **getting sick and helping them to recover.**

This leads to **too many people** being admitted to hospitals and discharged to **permanent care home places.**

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Which means there is **even less money available** to spend on helping people. This then leads to **even more hospital admissions and discharges to care homes.**

People think there should be more money given to **help people stay out of hospitals** and **support them to recover** when they come out.

Gaps in our knowledge

Although this issue has been widely **talked about and researched** over the years, there are some things we **don't know enough about.**

1. Most **research** into the amount of delays has been done by **medical and clinical researchers.**

They review the **case notes** of patients in hospitals, which have been **written by other medical professionals**.

There have been very few attempts to **involve older people, families, and front-line social staff** in research and conversations.

This means that any solutions put forward won’t include **lived experience and staff knowledge**. There is a danger to **miss things** that will **solve the problems**.

Our group IMPACT argues that **people are experts in their own experience**. People often know what works for them and they are the **only people** who go through their journey through services.

Many of the professionals **involved in someone’s care** often only know them at one moment in time. **They don’t see the whole picture.**

2. Some research is so focused on counting **how many delays** there are, and who they happen to, and **miss looking for solutions.**

An international review looked at good practice examples, so people can see what **solutions already work.**

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This article is free to read at: https://bmjopen.bmj.com/content/bmjopen/11/2/e044291.full.pdf

What happens next?

While we want this problem to be solved, **we know it is very complicated**. It is also something that has been a problem for **many years across the world.**

This is difficult because different areas of health care **don't always agree** the best way to do things.

Hospitals are focused on and rewarded **for being efficient**. This means getting someone in, treating them, **getting them out again** and using the bed for someone else.

Social care tends to be focused on things that matter to the person. Their work is focused on **helping people make big and difficult decisions** about their long-term needs.

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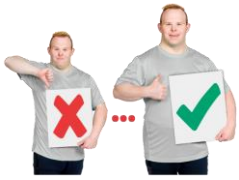
It’s not that one of these ways is right and the other is wrong, **they’re just different**. But sometimes these two different ways of doing things don’t **work well together**.

Focusing on what matters to older people



We know there **isn’t any magic answers** to these issues. But we might still be able to **make progress**.

We should focus on the **experiences of older people** and **what matters to them.**

Although nearly 30 years old, an **interesting example** comes from work by the **‘Fife User Panels’** project.

They talked to **lots of different people** about how they wanted to be treated **when leaving hospital.**

Their guide included things like making sure the person’s home was **ready for them**, there was **support in place**, and that they were **given plenty of notice.**

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There is also good practice examples from the **Social Care Institute for Excellence**. On twitter, there is a hashtag called #SocialCareFuture which has many **personal accounts from families**.

If you would like **more information** on either of these studies, please **contact our team.**

From this research, we think there’s a lot **different things health and support staff** can do.

We need to focus on what we can do beyond our **own roles and organisations**. We need to think about ways we can help make sure **support is as joined up as possible.**

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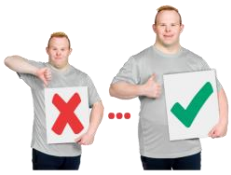
Rather than passing problems on to **others and getting frustrated**, we need to know that this is **often no one person’s fault.**

Local organisations need to have good relationships with each other and find practical ways to **solve problems together.**

People who write policy should look into **what can be changed** to make working together easier.



Doing these things would make changes on three different levels: **individual, organisational and structural**.

Individual means things people do on their own within their job or role. Like making sure **not to discharge someone when it would be unsafe.**

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Organisational means people do things **together in their workplace**. This could mean that a ward agrees to have things in place to **help people go home** when they are ready.

Structural is things like policy for the **whole country**. This could mean that anyone staying in hospital over a certain time **must have a review of their needs.**

We think that **co-ordinated** action is needed at **all three levels** if we are to make progress.

Key questions before our meeting

Here are a **few questions** to think about before our next meeting. You do not have to write anything down, but you may find **making notes useful**.

What are the main things about hospital discharge that you want to focus on **in your local Network**?

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How much do you know about the **experiences of older people** and what things matter to them?

Do you think people’s **experiences of discharge** are like the two stories we have in this document? **What other stories do you know?**

How much do you know about the experience of **front-line staff?** What do you think would make the **biggest difference to them**?

Can the work you do help people who experience **early or badly coordinated** discharges?

Have you tested **any improvements** over time to make sure that these changes can be stuck to?

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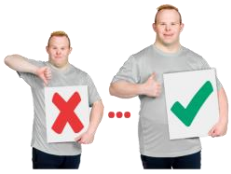

How will you make sure that you don’t just move a problem from one part of the system to another? How will you make sure we are improving the situation for everyone?

Final thoughts

We can provide a **reference list** for our sources, please message or email if you would like this **sent to you**.

Some of this document has been shortened for our **Easy Read version.** If you want any further information on different sections, **please let us know.**

Labels are for Jars, not People!
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