

PASSPORT TO HEALTH

A new passport scheme is helping improve the hospital experience for people with learning disabilities and their families. Jim Blair, Kirsty Glaysher and Sue Cooper outline how it works

What we understand by the term 'quality of life' varies from person to person and depends on our upbringing, our view of the world and what we see as being of worth. It can be easy to make assumptions about a person's quality of life, which can colour our judgements about the support, care and treatment of individuals, and how and what they should receive.

So it is vital that the person and those who know them best are involved in their care, so that a more complete picture of a person's life can emerge and their needs, likes and dislikes can be shared with those providing care and support. This should improve the quality of the care and treatment that a person receives.

It was with this in mind that the hospital passport was developed, containing important information about the person, such as their health and health difficulties, likes

and dislikes, and any medication that they may be on. The idea was adapted from one created by Gloucestershire NHS primary care trust and introduced at St George's Hospital in south west London.

It was created by people with learning disabilities and health professionals from Wandsworth and Merton Community learning disability teams and the acute hospital to ensure a better experience and health outcome for people with learning disabilities and their families in St George's.

Time for change

People with a learning disability are more likely to experience major illnesses that will require acute care (Disability Rights Commission, 2006) and more people with learning disability are living longer, and are therefore more likely to use health services as they get older. As a group, they experience more admissions to hospital (26%) compared to the general population (14%) (Mencap, 2004).

Valuing People (Department of Health, 2001) reported that people with learning disabilities get a 'worse deal' from health services than the rest of the population. Treat Me Right (Mencap, 2004) highlighted the poor quality of care people with learning disabilities received in both primary and acute secondary care. There is evidence that the basic human rights of individuals with learning disabilities, such as dignity, respect and equality, are not being met within the NHS and other health care settings.

The many recent reports and inquiries emphasise issues of ignorance and indifference to the needs of this group within health services and stress poor and inadequate care.

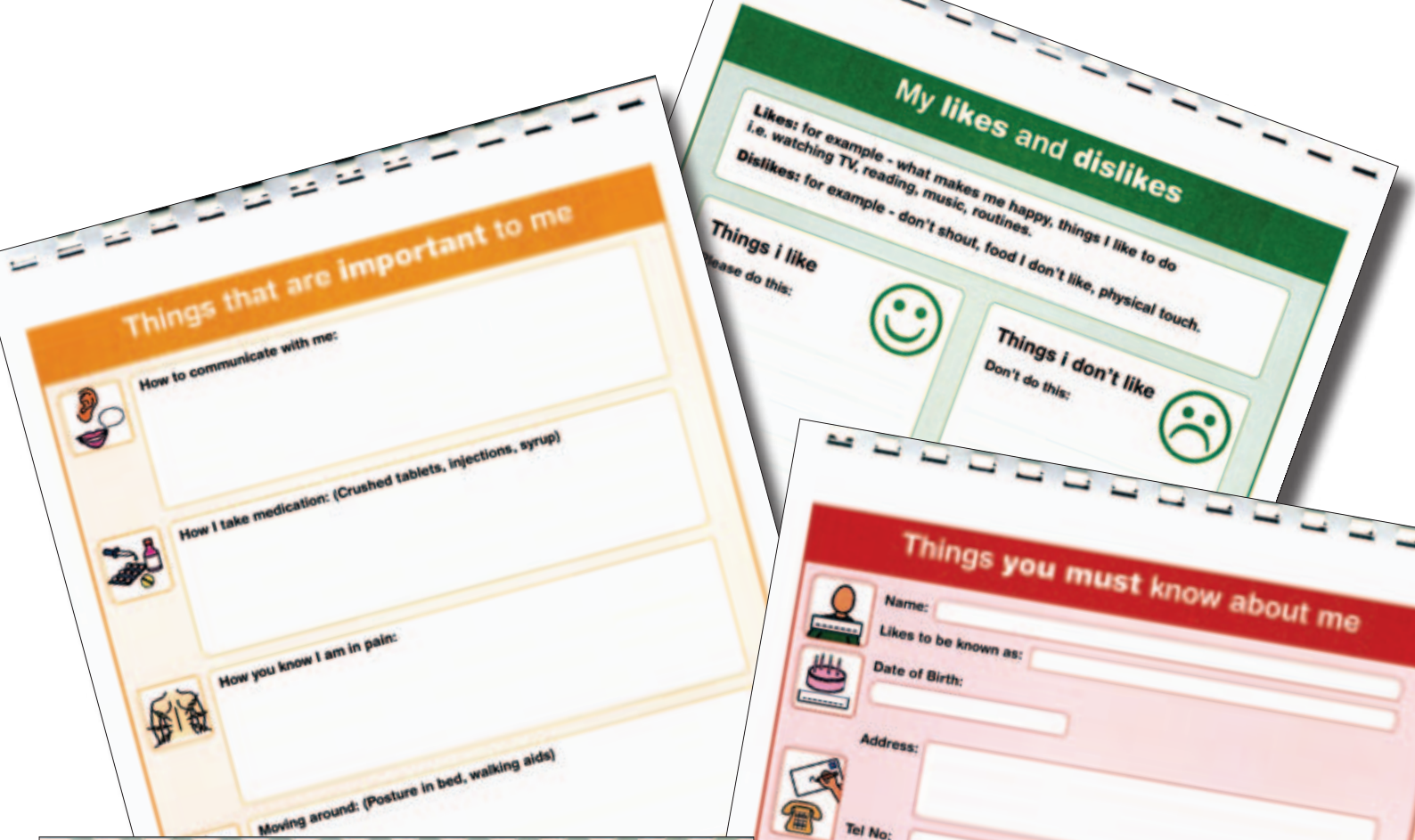
Death by Indifference (Mencap, 2007) argued that, in the cases it focused on, medical and health decisions were made based on assumptions about the individual's learning disability and their perceived quality of life and not on the life saving interventions required.

A report investigating these deaths noted: "the quality of care in the NHS and social services for people with learning disabilities is at best patchy, and at worst an indictment of our society". (Parliamentary and Health Service Ombudsman, 2009)

It also highlighted "distressing failures in the quality of health and social care" and found patients with learning disabilities were treated less favourably than others, resulting in "prolonged suffering and inappropriate care".

"Health service staff, particularly those working in general healthcare, have very limited knowledge about learning disability. They are unfamiliar with the legislative framework, and commonly fail to understand that a right to equal treatment does not mean treatment should be the same, but rather may need to be adapted to meet special needs." (Department of Health, 2008) ▶






This is my Hospital Passport

For people with learning disabilities coming to St. Georges Hospital

My name is:


If I have to go to hospital this book needs to go with me, it gives hospital staff important information about me.

It needs to hang on the end of my bed and a copy should be put in my notes.



This passport belongs to me. Please return it when I am discharged.

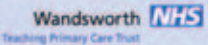
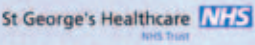

Nursing and medical staff please look at my passport before you do any interventions with me.



→ Things you must know about me

→ Things that are important to me

→ My likes and dislikes

Anna's story

Anna* a 45-year-old woman with Down's syndrome was admitted to a ward in a general hospital because of pneumonia in 2008. The staff, with the help of a community learning disability nurse, found out when filling in a passport with Anna that she is frightened of the dark, and so ensured that she had a bedside light by her at night.

They also found out that she likes Elvis Presley, and so prior to any procedures, for example blood pressure monitoring, they would talk to her about Elvis.

This example demonstrates how, by making small personalised adjustments, often at no financial cost, anything to enhance an individual's quality of care can be beneficial. *not her real name

Jim Blair with John O'Neil who helped to create the passport



National policy drivers including Valuing People Now (Department of Health, 2009) mean that all providers of health services are going to have to consider how they provide treatment and care for people with learning disabilities, and how they can improve and adapt access to all health services.

The passports

The passport is set out in an accessible manner using a traffic light coded system. The first pages in red cover the things you must know about the person. This is followed by yellow pages addressing issues that are important to the person. And, finally, the green pages cover their likes and dislikes. This provides a good overview of the whole individual.

The passports are filled in by people with learning disabilities and their supporters before or on admission. Passports have been distributed widely to people with learning disabilities by local community learning disability teams, various voluntary organisations, day services, residential services and GPs.

How they help

The passports are 'owned' by the person coming into hospital, which gives them a sense of being in charge of their health information. This information will assist them in ensuring that they receive the care and treatment that they have a right to.

Because the passport includes a wide range of information about the individual, not just their ill health, staff are able to reach a more comprehensive understanding of them as people who do have 'quality of life'.

Essentially, the passports, when complete, assist hospital staff to provide

better care for the person and their families and carers. The passports also educate health professionals to see the person and not their disability. This is going some way to addressing a number of negative issues that have been highlighted about the health service.

How they have changed care

The passports enable people to be genuinely engaged in their care as the passport travels with them through their hospital journey as well as when they leave. As a result, people's care and treatment is more personalised and dignified.

One person with a severe learning disability had in their passport that they were allergic to eggs. So the ward sister, having read this, contacted the person's residential home to find out if it was a serious reaction causing severe respiratory problems or a less dangerous rash. This is may not have been picked up if the passport had not been completed.

In another case, a person was told they could not eat or drink for a set period of time after a doctor had read in their passport that they bubble up liquids and regurgitate foods. This could indicate a severe swallowing problem known as dysphagia, which can lead to choking.

Each of these examples illustrates how the passport is having a direct positive impact on the care and treatment of people with learning disabilities.

The passports are now being used at St George's for people with dementia care needs, mental health problems, those who have experienced strokes, and for younger people. Early indications are that it is benefiting all these groups.

There is also scope for rolling it out further, for example for people whose first language is not English, or just for anyone who is concerned about communicating effectively as an inpatient.

By the end of 2009, the passport will be in use across all the acute trusts in south west London. This partnership approach forms part of the drive to improve the quality of care and treatment of people with learning disabilities in these

hospitals. It also demonstrates a desire to work together to ensure better care. The hospitals are also working on creating shared protocols and procedures for people with learning disabilities, for example in agreeing core reasonable adjustments, packs for clinical staff and the education of health professionals.

It is important that we all no longer accept health professionals stating they are 'doing their best' – we need to ensure they actually do what is necessary.

It is vital to ensure that we get it right for people with learning disabilities as, if we achieve that, then the hospital experience will be better for everyone. ■

About the authors

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Mencap (2007) Death by Indifference. London: Mencap.

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Resources

www.easyhealth.org.uk

www.intellectualdisability.info