

PRESS RELEASE

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Surrey and Borders Partnership pioneers UK's first easy-read guide about organ donation

A pioneering clinical psychologist at Surrey and Borders Partnership NHS Foundation Trust has, with a small team, created the country's first official guide to organ donation for people with a learning disability.

The new guide is designed to help people make informed decisions about end of life care and is in an easy read format – using large print, simple language and images to illustrate the key ideas.

Dr Karen Dodd, associate director for specialist therapies - learning disabilities, was planning how to help those who use the Trust's learning disability services to make end-of-life decisions when she noticed a lack of clear information on this issue.

She approached NHS Blood and Transplant (NHSBT) for additional resources and it confirmed it had produced nothing specifically aimed at this audience. They immediately agreed to work together to change that.

Karen said: "People with learning disabilities are living longer, fuller lives than ever before and it's essential that they get the support they need to make informed decisions about their care, including what happens to them at the end of their life. But despite these advances, people with a learning disability are still 2.5 times more likely to suffer from physical ill-health than most people, which makes it even more important that they can make their own decisions around organ donation. It's been incredibly rewarding to work on this project and exciting to think that this guide is now available nationwide, through NHSBT."

Research from NHSBT shows that almost everyone (96%) would accept an organ if they needed one but only just over a quarter (29%) have joined the NHS Organ Donor Register. So whilst more than 10,000 people in the UK currently need a transplant, an average of three a day die every year before a donor can be found.

Jane Griffiths, Regional Manager for Organ Donation at NHSBT, said: “This detailed and targeted leaflet will allow many more people to have access to the information that they need to make an informed decision about signing up to donate their organs. With over 10,000 people on the waiting list for organs in the UK it is essential that the message to sign up to the NHS Organ Donor Register (ODR) reaches as wide an audience as possible and enables all those that would want to have access to this choice.”

According to the Department of Health, around 2% of the population, or up to 1.2 million people in England, have a form of learning disability. Of those, up to 200,000 are at the more severe end of the spectrum.¹

National research in 2008 predicted a 20% growth in the number of people with a learning disability in England between 2001 and 2021, twice the demographic increase for the same period.² One explanation given for this was increased average life expectancy: in the 1930s this was estimated to be less than 20 years whereas today that has risen to 74, 67 and 58 for those with mild, moderate and severe learning disabilities respectively.³

The leaflet was launched at Big Health Service Check event - a regular event organised by the local NHS regional headquarters, NHS South East Coast, to encourage trusts in the region to provide better healthcare for people with learning disabilities. It is being distributed to health and social care professionals working with people with a learning disability in the community, in general hospitals and care homes across the South East, from Oxfordshire to Kent.

Funding for the print-run has come from Valuing People Now, a national initiative to increase access to health care for people who have a learning disability.

A pdf of the leaflet is also available from the NHSBT website at:

www.organdonation.nhs.uk/ukt/newsroom/publications/publications.jsp

Surrey and Borders Partnership has also developed a range of booklets to increase the awareness of End of Life issues for people with learning disabilities; for staff in these services, and for palliative care and acute hospital staff.

ENDS

Notes to Editors:

Surrey and Borders Partnership NHS Foundation Trust:

Surrey and Borders Partnership NHS Foundation Trust provides health and social care services for people with mental health illness, drug and alcohol problems and learning disabilities across Surrey and North East Hampshire. It employs over 3,000 people across 74 sites, serving 1.3 million people of all ages.

It also provides the following specific services across its borders:

- Learning disability social care services in both Croydon and Hampshire
- Minor provision of specialist mental health services in Croydon
- Drug and alcohol services in Hampshire

NHS Blood and Transplant:

- NHS Blood and Transplant (NHSBT) is a Special Health Authority in the NHS. It is the organ donor organisation for the UK and is responsible for matching and allocating donated organs. Its remit also includes the provision of a reliable, efficient supply of blood and associated services to the NHS.

Facts and Figures:

1 – Figures taken from 2008 report by the Centre for Disability Research at Lancaster University, which, quoting figures from the Department of Health's *Valuing People* initiative (65,000 children and 145,000 adults with the most severe conditions)

www.learningdisabilitycoalition.org.uk/download/People_with_Learning%20Disabilities_in_England.pdf

2 – Emerson & Hatton "Estimating the future need for adult social care services for people with learning disabilities in England"

http://www.learningdisabilitycoalition.org.uk/download/CeDR_November.pdf

3 – Studies looking at the life expectancy of people with a learning disability quoted on the Royal College of Nursing website: www.rcn.org.uk/development/practice/social_inclusion/learning_disabilities