

# national information forum

Working for the inclusion of disabled and other disadvantaged people  
by encouraging better information provision

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For members of the National Information Forum*

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## HERITAGE ON LINE

The November/December issue of the *Library + Information Gazette* draws attention to the fact that libraries are “increasingly embracing the virtual world of online services”. It focuses on how the Wigan Leisure and Culture Trust is putting the town’s photographic heritage on line, providing an exemplar of the opportunities offered by digital technology to manage archived stores of old photographs.

Here in Peckham a remarkable historical painting has recently come to light – in Australia! Dated 4 August 1834 and found wrapped (and preserved) in brown paper it depicts a row of early buildings on Peckham High Street. The excitement is that they are still there, listed but obscured by 20th century, single-storey, incongruous and nondescript shops. Regrettably the excitement does not appear to have penetrated through to Southwark’s councillors.

## ASSISTED DYING

A group, Healthcare Professionals for Change, has been launched to challenge the opposition of the British Medical Association and medical Royal Colleges to a safeguarded change in the law to allow terminally ill people the choice of assisted dying. It is chaired by Oxford GP Dr Ann McPherson CBE, who is herself dying of pancreatic cancer.

**Go to [www.healthprofessionalsforchange.org.uk](http://www.healthprofessionalsforchange.org.uk)**

Meanwhile, Jane Campbell’s Resistance Campaign, which asks MPs to resist changes in the law on assisted dying, has resulted in Dignity in Dying being “inundated” with messages from disabled people challenging her views (*Campaign*, Autumn 2010). At present the only recourse for those of us, disabled or not, who would wish not to endure a protracted death beyond that which nature intended, is to make an Advance Decision. But we are told that it is also important that this is updated at least annually.

**For detailed information contact Compassion in Dying, 181 Oxford Street, London W1D 2JT; tel: 020 7479 7731; e.mail: [info@compassionindying.org.uk](mailto:info@compassionindying.org.uk); website: [www.compassionindying.org.uk](http://www.compassionindying.org.uk).**

**Derek’s views on assisted dying were included in the December issue of the *Retired Fellows Society Newsletter* of The Royal Society of Medicine.**

## AGE OLD PROBLEMS

### Hospital care

The National Confidential Enquiry into Patient Outcome and Death



(NCEPOD) has published a report *Elective and Emergency Surgery in the Elderly*. It focuses on the care of those patients aged 80 or over who died within 30 days of such surgery in the three month period 1 April to 1 June 2008, casting a critical eye on where care might have been improved, and identifying remediable factors in their clinical or organisational care. Disturbing reading, especially for those who think care is preferable to opting out.

**Go to [www.ncepod.org.uk](http://www.ncepod.org.uk); report in *The Guardian*, 11 November 2010**

The Patients Association has published a report *Listen to Patients, Speak up for Change* which brings together 17 first-hand accounts of the care received by older patients in NHS hospitals. Chosen from the experiences of people who have contacted the Patients Association helpline in the past year, they are said to highlight serious failings in standards of nursing care, poor communication with relatives and an ineffectual complaints handling system.

Go to [www.patients-association.com/News/404](http://www.patients-association.com/News/404).

The Dr Foster organisation has launched its 2010 Hospital Guide. This makes the basic point that patients need information to ensure that they get the care that is right for them, know what best practice is and are able to demand it. It is claimed that such information is provided through [www.drfoosterhealth.co.uk](http://www.drfoosterhealth.co.uk), where the guide can be viewed or downloaded. It goes on to report some facts about English hospitals:

- 62,800 adverse medical events have been reported between April 2009 and March 2010
- there is an underreporting of such events
- despite an improvement in mortality rates and a narrowing of variation between hospitals, 19 hospitals were found to have significantly high overall mortality ratios and four with significantly high ratios for deaths after surgery – with two named trusts having high ratios across both.

### **Care homes**

We note that although there are some excellent care homes, a good many fall below acceptable standards. Over the past year some 93 homes and agencies were shut down by the regulator, the Care Quality Commission (CQC), but the BBC reports that their investigation found that a dozen of them were still open under the same owners. In some cases homes had been allowed to close; only, under present rules, to reopen on the same day. The BBC claims (Fran Abrams, 23 November) that “Damning reports about their past records were then removed from the CQC’s website, so potential residents and their relatives could no longer read them”.

A phone-in on BBC Radio 5 Live produced a chorus of criticism, not only of homes themselves but also of the regulatory system. It was asserted that “nobody listens at the top” and that inspections were commonly bureaucratic, box-ticking exercises. Too often the regimes of the homes themselves were institutionalised, with a lack of personal sensitivity, and horror stories abound. The charity Compassion in Care has regularly drawn attention to this sort of thing. Under the new “lighter-touch” inspection system, with a 43% cut in the number of inspectors, it seems to us that things can only get worse. We wonder if the government should introduce an Advance Decision allowing us to decline internment in a care home.

**Go to [www.compassionincare.com](http://www.compassionincare.com). Report at [www.bbc.co.uk/news/health](http://www.bbc.co.uk/news/health)**

### **NHS SPENDING**

We recall, many years ago, attending a lecture at St Thomas’s Medical School when Enoch Powell (fixing Derek with a penetrating stare) spoke about the finite limits of NHS expenditure. The memory was triggered by reading a discussion between David Attenborough and Richard Dawkins published in *The Guardian Weekend* on 11 September which ended with them being asked what they saw as the most difficult ethical dilemma facing science today. Both agreed it was how far one should go to preserve individual human life. (Attenborough was 84, Dawkins 69).

### **CONTINUED DETENTION OF THE INNOCENTS**

In issue 22, June 2010, we reported with delight that the Government had announced its commitment to ending the detention of children for immigration purposes, described by Nick Clegg in July as a “moral outrage”. Sadly the Home Office has now confirmed that the practice will not be brought to an end before March 2011 at the earliest. We wonder if this falls within Ian Duncan Smith’s definition of sin.

*The Observer* (28 November) reported heavy criticism from BID (Bail for Immigration Detainees) and the Refugee Council of new alternative “open” centres currently planned by the Home Office.

### **AND THE FORCIBLE REMOVAL OF IMMIGRANT FAMILIES**

BID and The Children’s Society had previously (19 November) issued a briefing paper outlining their concern about two of the methods of forcibly removing families being trialled by the UK Border Agency: limited notice of removal and accommodation centres.

Though it recognises the inevitability, under our current arrangements, of the forcible removal of some families, it draws attention to clear evidence from overseas that far fewer families end up facing forced removal if overall improvements are made to the immigration and asylum system. For example, in Sweden 82% of all returns of refused asylum seekers in 2008 were made voluntarily. By comparison, in 2009, only 14% of returns of asylum seekers and migrants from the UK were made through the Assisted Voluntary Return schemes.

**The full statement is available at [www.biduk.org/454/news/](http://www.biduk.org/454/news/).**

### **A NEW BRITISH STANDARD FOR WEB ACCESSIBILITY**

The December issue of the RNIB’s magazine *NB* carried an article by Steve Griffiths on the new Code of Practice BS 8878. It has been designed, writes Steve, “to introduce accessibility, usability and user experience for disabled people to non-technical professionals”. The standard takes account of other recognised guidance such as WCAG(2) and aims to help organisations comply with the law and open up their products and services to a wider audience.

### **A MESSAGE FROM THE EQUALITY TRUST**

The coalition government was right to say that it is unfair to burden our children with debt, but in the rush to reduce the deficit this commitment to “fairness” seems to have been forgotten. The Institute for Fiscal Studies described the spending review as “regressive” and according to the Treasury’s own figures, it is the poorest 10% who will pay proportionally more than any other group as a result of the measures the review introduced. It also goes without saying that impending housing insecurity and job losses threaten to increase the gap, rather than narrow it.

Yet cutting public spending is not the only way to address the deficit – and the most vulnerable people in society should not be paying for the bankers’ mistakes. The New Economics Foundation estimates that up to £100 billion of public money is lost annually through tax avoided, evaded or uncollected. The savings made from additional welfare cuts of £7 billion are tiny by comparison and we call on the coalition to live up its motto that “we’re all in this together” by cutting the deficit through measures that decrease, not increase, inequality.

**From the Trust’s magazine *Among Equals*.**

Ed: As far as disabled people are concerned, the RNIB magazine *NB* (December) comments that with only a handful of exceptions, disabled people and support organisations feel the Comprehensive Spending Review is not, as the government claims, “fair”, nor does it put the burden of spending cuts on “those with the broadest shoulders”. Instead, they expect the cuts to have a disproportionate impact on people who are already disadvantaged.

### **COUNTING THE COST 2010**

Contact a Family has published a report which highlights the extreme financial pressures faced by many families with disabled children. Based on a survey of over 1,100 respondents carried out between February and April 2010, CaF found high levels of deprivation, including almost a quarter going without heating, many falling behind on debt repayments and over half reliant on their wider families or friends to make ends meet. Go to [www.cafamily.org.uk](http://www.cafamily.org.uk) for details and recommendations.

### **THE NHS ATLAS OF VARIATION IN HEALTHCARE**

This brave initiative, combining input from a wide range of organisations and edited by Sir Muir Gray and Philip DaSilva as part of the NHS QIPP (Quality and Productive Case Studies) Right Care Programme, presents a series of maps of England colour coded to give a broad indication of variations in healthcare. The Atlas has 34 maps on 17 chosen topics:

- cancers and tumours
- endocrine, nutritional and metabolic problems
- mental disorders
- neurological problems
- problems of vision
- problems of circulation
- problems of the respiratory system
- problems of the musculo-skeletal system
- problems due to trauma and injuries
- problems of the genitor-urinary system
- maternity and reproductive health
- screening
- older adults
- end-of-life care
- organ donation
- diagnostic services
- prescribing.

It is accepted that there are a number of factors that provide natural explanations for variations in care, primarily that the data could be more accurate and that the populations needing care across the country are different, notably in the numbers of older people and levels of deprivation, giving rise to disparate disease patterns. But although some of the variation might be warranted by such divergence of need, the authors conclude that the major part is unwarranted and should be addressed.

A particularly striking example of variation is that revealed by map 3 in the second of the above topics. This charts the incidence of major amputations in the five years between 2004/5 and 2008/9 per 1,000 patients with registered type 2 diabetes across ten strategic health authorities. It shows, for example, that the rate in the South West is almost twice that of the South East. The charity Diabetes UK regards the variations as “shocking”, and argues that the majority could have been prevented. There are more than 70 major amputations a week carried out on type 2 diabetes patients in England, 80% of which are thought to be potentially preventable.

Map 6 within the third topic is also particularly interesting. It charts the directly standardised rate of suicide mortality per 100,000 population across 152 primary care trusts. The context is illuminating.

Around 5,000 people a year in England take their own lives, and suicide is the most common cause of death in men under the age of 35. People with severe mental illness also have a startlingly enhanced rate (a 12-fold increase), even more so people in prison (a 20-fold increase among female prisoners) and those with a history of deliberate self-harm (a 30-fold increase). The mortality rate for all suicides varies by geographical area and social class, with a seven-fold variation between the highest and lowest PCTs.

We think this atlas will be sufficient to alert anyone and everyone who can play some part in reducing what must be seen as one of the most disturbing examples of inequality in England. It is available at [www.rightcare.nhs.uk/atlas/](http://www.rightcare.nhs.uk/atlas/). Hard copies, while stocks last, are available via the website. A BBC report is at [www.bbc.co.uk/news/health-11832233](http://www.bbc.co.uk/news/health-11832233).

## **NATIONAL TRUST**

It's good to have something solid in a changing, unequal nation. Trust membership offers free admission to over 300 historic houses, more than 180 gardens and most of the Trust's car parks. It also allows free admission to properties owned by the National Trust for Scotland. Admission policy also allows free admission on request for an essential companion or carer of a disabled visitor, whether a member or paying an admission charge. To save having to repeatedly request a companion's free entry it is possible to apply to the Access for All team

(contact details below) for an 'Admit One' card in the name of the disabled visitor.

We have received the 2011 *Access Guide*, which must now be described as a book. It describes the specific access facilities at Trust properties. As before it is available free of charge from the Trust's 'Access for All' team at Heelis, Kemble Drive, Swindon, Wiltshire SN2 2NA; tel: 01793 818531; e.mail: [accessforall@nationaltrust.org.uk](mailto:accessforall@nationaltrust.org.uk). The guide is also available in large print from the membership department at PO Box 39, Warrington WA5 7WD; tel: 0844 800 1895 (voice) or 0844 800 4410 (minicom); e.mail: [enquiries@nationaltrust.org.uk](mailto:enquiries@nationaltrust.org.uk). A tape or CD version can be obtained from SoundTalking on 01435 862737; e.mail: [admin@soundtalking.co.uk](mailto:admin@soundtalking.co.uk).

## **SMOKING**

The RNIB reports on research presented at a recent National Cancer Research Institute conference. This shows that, despite the recession, fewer smokers are trying to kick the habit. Whereas in 2007 around 32% of smokers had tried to quit within the previous three months, the figure for 2008 fell to 23%, for 2009 to 22% and for 2010 to 17%. Professor Robert West, director of tobacco studies at Cancer Research UK's Behaviour Research Centre, is quoted as saying that very few smokers use the most effective methods to quit. The NHS Quit Smoking services (<http://smokefree.nhs.uk>) are used by only 5% of smokers despite being four times more effective than other methods.

The article points out that nine out of ten cancers are caused by smoking and half of all long-term smokers will die from the addiction. It is also a major cause of sight loss.

## **FROM RUSSIA WITH RELIEF**

We laid on the line our distaste for the ways of modern football in issue no.4 (September 2008). It has become, at least for men, an obsessive addiction that distracts attention from things that matter – the modern equivalent of 'opium for the people'. Thus we think Fifa, whether or not immaculately, has done us all a good turn. Likewise Simon Hoggart in *The Guardian* (4 December), who comments "Just think: terrible communications, lousy food, bad hotels, awful service, ludicrous prices and an aggressive drinking culture – thank goodness England didn't win."

## **ARTHRITIS CARE**

Congratulations to this outstanding charity for the quality of its information. In this year's British Medical Association Awards its patient information leaflets and factsheets won no fewer than seven commendations. The BMA deserves praise too, for these awards have consistently driven up standards of information provision. In 2010, entries to the patient information awards were up 11 per cent on the previous year, and 55 per cent more organisations applied. It is also interesting to read that 1 in 3 GP appointments concern some form of arthritis.

## **WANTED: A BETTER DEAL FOR CARERS**

On 14 July 2010, Barbara Keeley, the MP for Worsley and Eccles South introduced a private member's bill under the Ten Minute Rule to:

- require health bodies, GPs and certain other organisations to identify patients who are carers or who have a carer
- require identified carers to be referred to sources of help and support and to make further provision in relation to such arrangements
- make provision in relation to the responsibilities of local authorities and schools for the needs of young carers and their families.

A second reading debate is scheduled for 4 February 2011. With the prospect of cuts in local authority services and a coalition government that appears to see the disabled community as a soft target, here is a real opportunity to do something positive. **You can follow progress of the Carers (Identification and Support) Bill at [www.parliament.uk](http://www.parliament.uk).**

Meanwhile there is some good news in that the right of complaint to the Local Government Ombudsman enjoyed by people in local authority care has, from October 2010, been extended to those who arrange and fund their own adult social care. **Go to [www.lgo.org.uk/adult-social-care](http://www.lgo.org.uk/adult-social-care), or phone 0300 061 0614.**

## **STRIPPING FOR MS**

Three women who live with multiple sclerosis have stripped off in beautiful and remote Lake District locations for a new fundraising calendar. Award-winning photographer Steve Yates shot the “classy black and white images” for the December picture of the 2011 calendar of the MS Society. Keswick Lions paid for the calendar to be printed. It is available from [www.everybodysmile.biz/derwentphotography/ports/index.html](http://www.everybodysmile.biz/derwentphotography/ports/index.html), priced at £10 + £3 p&p. All proceeds go to the MS Society.

**From a report in the December/January issue of ‘All Together Now’. We should point out that the figures are in silhouette.**

## **EYE CARE FOR PEOPLE WITH LEARNING DISABILITIES**

SeeAbility ([www.seeability.org](http://www.seeability.org)) has an ongoing ‘eye 2 eye’ campaign to improve and increase accessibility to regular and effective eye care for people with learning disabilities. It points out that one in three people with a learning disability has a sight problem, but that they are least likely to get the right help and support with eye care. A dedicated website, [www.lookupinfo.org](http://www.lookupinfo.org), provides relevant information for carers, supporters and eye care professionals, including an online film and easy read fact sheets.

## **PLAIN ENGLISH**

The December issue of *Plain English* examines the possibility that the use of confusing financial jargon may have contributed to the credit crunch and a lack of understanding in bankers’ financial products. It is asking why we have no Plain English Act in the UK, nothing having come of two bills on the subject. It is asking all concerned to sign its Plain English Charter at [www.plainenglish.co.uk/plainenglishcharter](http://www.plainenglish.co.uk/plainenglishcharter). It points out that using plain English not only keeps information clear, but saves words, time and money for everyone.

We are delighted to learn that in July founder Chrissie Maher gained an honorary fellowship from Liverpool’s John Moores University.

## **UNIFICATION DEBATE**

The November/December issue of *Independently* reports on a debate at the AGM of the National Centre for Independent Living on its proposed unification with RADAR and the Disability Alliance. Notwithstanding some reservations, a resolution was passed instructing NCIL’s Board to move forward in working with RADAR and the Disability Alliance to create a unified organisation by the summer of 2011 and to report back to a general meeting of NCIL next spring (16 member organisations for, none against, one abstention).

## **INFORMATION SUSCEPTIBLE TO CUTS?**

We read that the Museums, Libraries & Archives Council is to be disbanded and its functions transferred to Arts Council England, along with £46 million to cover the additional work. But the CEO of the Chartered Institute of Library and Information Professionals, Annie Mauger, has concerns as to whether ACE, despite its experience in promoting and developing the arts, will be able properly to support libraries in all their functions. Libraries, she points out, have more than an ‘arts’ role. They play an essential role supporting the information and literacy needs of their communities.

**Based on a report in Library and Information Update, December 2010.**

## **WE HATE NO. 37: TUITION FEES**

*“Studenti! Udite...Là la vittoria o il Nulla!...Ah, comincia l’Epoepa! L’Università! “*

*“Students! Hear me...There is victory or nothing...Ah, the epic story is beginning! The University!”*

Luigi Illica: ‘Germania’, 1902 (libretto to Franchetti’s opera).

So we hate tuition fees? Well not altogether. Rather the mess that has been made of the way that the coalition government has gone about increasing the contribution to be expected from students in England from 2012. A university education is not a universal benefit. It confers advantage upon those who end up with a degree and as such it is not unreasonable that students should pay (should have paid) something for the privilege. But the state too benefits from raising the standards of the potential workforce and the intellectual strength of our meritocracy. The trick is to strike the right balance, avoiding the kind of precipitous change that has brought

students on to the streets. The Labour government introduced modest tuition fees, a measure which, if not popular, did not threaten revolution. But that fees should, at a stroke, be almost doubled or even trebled in “exceptional” circumstances could be predicted to upset even our normally tranquil student population.

Our first objection is that the increases are an affront to fairness (which the coalition claims to espouse). What would we think if the price of biscuits suddenly went up by approaching 100% (or 150% in the case of Duchy originals)? Particularly if biscuits were free in other parts of the United Kingdom. The scale of the increase is Draconian, the consequence of a cut too far in the support provided by the state. And what do we think of such increases being proposed and supported by parliamentarians who themselves have enjoyed a university education free of charge? How “together” is that? Then, to aggravate the situation, what if some of those parliamentarians have been elected on a solemn pledge not to increase tuition fees? It is as though those who had committed to abstain from and not provide alcohol then took jobs in a public house.

It is pointed out that nothing needs to be paid ‘up front’; that the charge is by way of a loan, repayable only if and when the graduate’s individual’s salary reaches £21,000. But the effect of this provision is cumulative. It forces repayment of a substantial debt upon all those who make a reasonable (even modest) success of their careers. And although the starting gate will be the same for everybody, the background economic circumstances of some and therefore their ability to pay will be quite different from others. Many from poor backgrounds have no wealthy parents to whom they can turn for help. Such aspiring students realise this, and will face an enormous disincentive to embarking on a university course.

Our second, and profound, objection is the haste with which these measures have been brought forward. Consultation with student bodies might have avoided the reaction that has been provoked. If some reasonable increase was necessary to help reduce the national deficit it might have been discussed and staged.

On the whole, if administratively it could be put in place, we think a graduate tax related to income would be a fairer option; and why not make it apply not only to new but also to former graduates who are still in work. Could not this information be brought within the existing tax return?

We do not condone the rioting that has occurred, but we understand it.

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**This briefing has been compiled by Ann Darnbrough and Derek Kinrade. The views expressed do not necessarily represent those of the National Information Forum. Earlier briefings and the ‘We Hate’ series are available on the Forum’s website: [www.nif.org.uk](http://www.nif.org.uk).**