

Time To Save Lives

A SOFT OPT OUT SYSTEM FOR THE UK

TIME FOR CHANGE

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TIME TO SAVE LIVES –A SOFT OPT OUT SYSTEM FOR THE UK

Summary

- In the UK more than 10,000 people are currently waiting for a transplant.¹
- Across the UK 3 people die every day waiting for a transplant, in Wales someone dies every 11 days on the transplant waiting list.
- The number of people in the UK needing an organ rises year on year², yet the number of organs donated remains amongst the lowest in Europe.
- In May 2010 the British Medical Journal published an analysis³ which showed that on even a conservative estimate an extra 2880 extra donors would have given organs under an opt out system.
- This was supported by other studies⁴ which confirm that a move to presumed consent increases the organ donation rate by up to 30%.
- Different systems of presumed consent for organ donation have already been introduced in Spain, Belgium, Sweden, Denmark, Finland, France, Italy and Norway saving thousands of lives each year.
- The Welsh Assembly Government, supported by Kidney Wales is proposing to introduce legislation to introduce a system of “soft” Opt Out⁵, in which the people would be presumed to be organ donors after death unless :
 - they have opted out
 - they cannot be identified
 - their place of residence cannot be identified
 - the wishes of the deceased can be proven to be contrary after relatives have been contacted
 - Immediate relatives object.
- Under a ‘soft’ opt out system there is no compulsion. No one donates organs unless they want to do so.
- It is widely recognised that a successful switch to an opt out system must be accompanied by an increase and transplant infrastructure. This is already

¹ http://www.uktransplant.org.uk/ukt/statistics/latest_statistics/monthly.jsp

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http://www.uktransplant.org.uk/ukt/statistics/transplant_activity_report/current_activity_reports/ukt/2008-09/transplant_activity_uk_2008-09.pdf

³ S Bird and J Harris Time to move to presumed consent for organ donation. British Medical Journal, BMJ 2010;340:c2188

⁴ Abadie A, Gay S. The impact of presumed consent legislation on cadaveric organ donation: a cross-country study. Journal of Health Economics 2006;25 :599-620

⁵ Opt out throughout this documents refers to a system of soft opt out organ donation

happening in Wales, with the development of a new Transplant Unit and the appointment of a national network of Clinical Leads on Organ Donation and donation co-ordinators.

1. THE UNITED KINGDOM CONTEXT

1.1 There is currently an insufficient supply of donor organs to meet the demand for organ transplantations in the United Kingdom and worldwide. The UK active transplant waiting list is increasing, and the ageing population and increasing incidence of type 2 diabetes are likely to exacerbate the shortage of available organs.

1.2 In 2006 the UK Organ Donation Taskforce⁶ was established to identify barriers to donation and examine ways in which organ donations could be increased within the current legal framework. Its report entitled 'Organs for Transplants' which was published in January 2008, said that "the current co-ordination system in the UK has developed in an ad hoc and unsystematic way over many years". It also found that current organ retrieval arrangements are "not sustainable in many areas of the country and are not able to support the required increase in donor numbers."

1.3 The Taskforce's main recommendation was to establish a UK-wide Organ Donation organisation to identify and allocate organs on a UK basis. It also called for a doubling of the number of transplant coordinators; the creation of an organ donation "champion" in each hospital trust, and improvements in the processes of identifying potential donors and the monitoring of donation activity in all hospitals.

1.4 Consideration of a change in the law to a system of presumed consent was outside the scope of this inquiry. However the Taskforce conducted a separate special inquiry⁷ later in 2008 into the possibility of opt out in the UK. It concluded that it should not be introduced in the UK at the present time.

1.5 While Kidney Wales welcomes much needed improvements to the transplant infrastructure across the UK, it believes that a significant gap will remain between the number of donor organs needed and the number of organs available for transplant unless opt-out legislation is also introduced.

1.6 Adabie and Gay suggest in their 2005 study that an increase of the magnitude they expect from presumed consent (25-30%) "*could potentially close the gap between the demand and the supply of organs in the UK.*"

1.7 In May 2010 the British Medical Journal published a study estimating that an additional 2880 organ donors would have been available in the last ten years if an opt out system had been in place. The paper's authors, Bird and Harris, also questioned the legitimacy of the UK wide enquiry into presumed consent.

⁶ UK Organ Donation Taskforce report entitled 'Organs for Transplant', published January 2008
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_082120.pdf

⁷ UK Organ Donation Taskforce inquiry into presumed consent, report published November 2008 titled '*The potential impact of an opt out system for organ donation in the UK*
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_090303.pdf

“There are only two options for me. Either I will receive a transplant or I will die. Opt out organ donation will mean that more people donate their organs – and we know that most people want to”. **Elliw, 34. Waiting for a kidney and pancreas**

4.7 There have been some moves in Westminster to introduce a system of opt out organ donation; most recently with Jeremy Browne MP’s Private Members Bill. Debate in Westminster has not yet progressed as far as in Wales.

4.8 Public attitudes towards opt out organ donation through surveys carried out in the UK and elsewhere show strong public support for a change in the system. The most recent survey carried out by YouGov⁸ in December 2009 showed that people in Wales back a soft opt out system two to one. This corresponds with UK wide levels which showed a near identical level of support in 2007.

2. LEADING THE WAY

2. 1 The Case for a change in the law

2.1.1 10,000 people in Wales⁹ have renal disease with the number effected rising dramatically. In Wales the number of people needing a Kidney transplant has risen by 51.7% in the last six years. This trend is similar to that across the UK which has seen the number needing kidney transplants rise by 44.6% in the same timeframe.¹⁰

“Living on dialysis is hell. It’s not a life – you’re existing, not living. I was lucky enough to get a second kidney after the first one failed when I was 12. The best thing is that I’m now a completely ‘normal’ person for the first time in my life. When it comes to donating an organ, the main question I’d ask people is: “Why not?” If you can’t think of a valid reason, why not? It’s a gift of life, it can give someone a life back – I’m proof of that.” **Hanna, 22. Kidney Transplant recipient**

2.1.2 As of April 2010 7,951 people are waiting for a transplant in the UK¹¹ Of those 6,867 need a kidney, 349 need a new liver; and 120 need a new heart. In Wales nearly 500 patients are currently waiting for an organ transplant.

“Having personally witnessed the anguish and grief in the patients unable to obtain a transplant, I firmly believe that we can no longer stand by and see organs being wasted which could potentially save lives, without a broad informed public debate about the way forward. Wales has a unique opportunity to lead the way for patients with end organ failure within the UK.” **Dr Richard Moore – Consultant Nephrologist and Clinical Director of Renal Services and Transplantation at the University Hospital of Wales, Cardiff.**

⁸ <http://shakespeare.yougov.com/2010/01/05/71-of-welsh-would-donate-their-organs-to-help-others/>

⁹ National Service Framework for Renal Disease launched by Welsh Assembly Government in 2007. <http://www.wales.nhs.uk/sites3/home.cfm?orgid=434>

¹⁰ Figures from NHSBT, available on request.

¹¹ http://www.uktransplant.org.uk/ukt/statistics/latest_statistics/latest_statistics.jsp

2.1.3 Organ Donor Register promotion creates awareness but does not solve the problem, increasing the number of people on the Organ Donor Register alone is not enough. With leading academics in agreement “*the current policy [opt in], however reinforced, will not substantially increase the number of organs available*” (Bird and Harris).

2.2 Organ Donation across Europe

2.2.1 Opt out organ donation is not a novel concept. It has already been introduced in Spain, Belgium, Sweden, Denmark, Finland, France, Italy and Norway.

2.2.2 Spain runs a "soft" opt-out system, where even if the person has not themselves opted out of donation while alive, the views of relatives are sought and they can refuse consent. Other countries, such as Austria, run a far stricter system where the views of relatives are not taken into account at all. In both these examples, the use of presumed consent coupled with improved transplant infrastructure, has boosted the availability of organs for transplant.

2.2.3 Belgium introduced its “soft” opt-out system in 1986 and increased the number of transplant co-ordinators at the same time. Just 2% of the population has opted out of organ donation – and the national rate of organ donation rose by 55% within five years.

2.2.4 The latest figures show that in Belgium there were 291 deceased organ donors in 2007 compared to only 51 in Wales – Belgium has one of the highest rates of donors per million people in the world.¹²

2.2.5 The evidence of a link between systems of presumed consent and increased organ donation is compelling. In 2003 a study “Presumed consent and other predictors of cadaveric organ donation in Europe¹³”, demonstrated that presumed consent was one of four variables which emerged as a significant predictor of cadaveric organ donation rates. In countries where Presumed Consent was a policy, there were a substantial number of additional organs available.

2.2.6 These findings were supported by a study published in the British Medical Journal in January 2009 investigated the impact of presumed consent for organ donation and once again found an increase in donation rates following the introduction of a system of presumed consent.¹⁴ This analysis is further support by the findings of Abadie and Gay of Harvard and Chicago Universities, which examined 22 countries who had introduced presumed consent systems over a 10 year period, found that presumed consent had a positive and sizeable effect on organ donation rates of some 25%-35% higher on average in these countries.

¹² http://www.eurotransplantcoordinators.org/uploads/pdfs/Irodat/02_Irodat%202008.pdf

¹³ Gimbel RW, Strosberg MA, Lehrman SE, Gefenas E, Taft F. Presumed consent and other predictors of cadaveric organ donation in Europe. *Progress in Transplantation* 2003;13(1):17-23

¹⁴ http://www.bmj.com/cgi/content/long/338/jan14_2/a3162

3. MOVING AHEAD TO A SYSTEM OF SOFT OPT-OUT

3.1 Kidney Wales proposed that the law on consent for organ donation be changed to encompass a “soft” system of Presumed Consent. This system proposes that for purposes of disease treatment Welsh residents are presumed to be organ donors on death unless:

- They have opted out
- They cannot be identified
- The person’s place of residence cannot be identified
- The wishes of the deceased can be proven to be contrary after relatives have been contacted
- Immediate relatives object.

3.2 There is now considerable cross party support for moves to a system of soft opt out across the UK

3.3 In July 2008 the Assembly’s Health, Wellbeing and Local Government Committee published its report following an inquiry into presumed consent. (12) The Committee issued its report to the Minister advising against a move to opt out organ donation at this time. However, a number of senior AM’s on the committee supported a dissenting report that the time had come to move to an opt out system.

3.4 In December 2009, Health Minister Edwina Hart announced that she would pursue legislative means to introduce a ‘soft’ opt-out system for presumed consent on organ donation in Wales. Her announcement followed a series of public debates and consultation throughout 2009 which revealed support for a change in the law to a system of soft opt out.

3.5 The BMA in Wales has welcomed moving to a system of ‘soft’ presumed consent, claiming a change in the law would “at a single stroke, save lives whilst still giving the individual the right to have a choice.”

‘Let’s show that we still care deeply about the health of our nation and that we are willing to lead with bold initiatives whilst other countries dither and waver.’ **Richard Lewis BMA Welsh Secretary**

3.6 At present the UK has one of the lowest rates of organ donation in Europe at just 13 donors per million of population. Spain has the highest organ donation rate in Europe at 35 donors per million of population (pmp).

4. TRANSPLANT CAPACITY

4.1 Existing infrastructure

4.1.1 At present there is one transplant unit in Wales, occupying a half of one ward, based at the University Hospital of Wales. Many patients in North Wales receive their transplants in England which is also where all paediatric transplantation takes place.

4.1.2 The Transplant Directorate of the University Hospital of Wales (UHW) in Cardiff is currently the only Transplant organisation within Wales and is responsible for kidney and pancreas transplantation in South, West and Mid Wales. It is also responsible for zonal retrieval of pancreata all around Wales and is the zonal retrieval team for non heart beating kidneys for all of South and West Wales.

4.1.3 The Directorate has performed more than 2,100 transplants over 30 years. There has been a significant increase of kidney and pancreas transplants in the last year with 113 transplants being performed, an increase of 22% compared to the previous year. (13)

4.1.4 Kidney transplants for patients in North Wales are carried out mainly in Liverpool in the Royal Liverpool Hospital. Transplants for Welsh patients are also carried out in Bristol and elsewhere, particularly for hearts and lungs.

4.2 Increasing Resources

4.2.1 It is widely recognised that there must be a substantial increase in resources and infrastructure to allow more transplants to take place in Wales.

4.2.2 Major steps have been taken in recent months to deal with these underlying problems of transplant capacity. Kidney Wales welcomed the major announcement from Health Minister Edwina Hart AM in December 2007 that Wales is to have a new state-of-the-art Transplant Unit, which will almost double the number of transplants carried out every year.

4.2.4 Another important aspect of transplant capacity is the number of co-ordinators available and the networks underpinning organ retrieval. This matter has been addressed comprehensively and honestly in the recent report of the Organ Donor Taskforce for the UK. Wales already complies with the recommendation to commemorate donor families by dedicating a stone in Cathay's Park in Cardiff in October 2007.

5. CHANGE AND AWARENESS

5.1 Widespread public engagement

5.1.1 Increasing awareness about soft opt out is key to winning the support of the public for a change in the law. It is also crucial if soft opt out is to be a success because under the system, if someone has failed to opt out but would not wish to donate, family members will be still be able to say no.

5.1.2 The most commonly reported reason for declining organ donation at present, according to co-ordination teams in Wales, is because the family member felt the need to protect the body of the deceased. Other factors include circumstances at time of death; the need for more time to come to terms with the death of their relative, or that they did not have enough information about what organ donation meant.

5.1.3 Even with a “soft” system of Opt Out, discussions with family members are crucial and need to be conducted properly and professionally.

5.1.4 Better information and support for families is vital if more are to give consent. Improved awareness will be just as important in a system of soft-opt out. Implicit in that, is that health professionals who discuss these issues with families also receive appropriate support and training.

5.2 Next Steps

5.2.1. Legislation to introduce a system of ‘soft’ Opt Out on presumed consent is currently being pursued by the Welsh Assembly Government.

5.2.2 The legal basis on whether the Assembly can bring forward an LCO (Legislative Competence Order) on Presumed Consent has been established both in the initial Committee hearing on 30th January 2008 and in the content of the submissions received from Kidney Wales and other organisations.

5.2.3 Having settled the matter of whether it would be legal for Wales to move forward on its own with regard to Opt Out, it has been debated whether Wales *should* do so alone. Kidney Wales would encourage the UK as a whole to change the law on organ donation, but believes that Wales has the will and capacity to take the lead. A position supported by the Welsh Assembly Government’s Health and Well being Committee when considering the issue. “we looked at the current legal position and whether there was any fundamental reason why Wales could not seek the power to introduce presumed consent in Wales, if there is the will to do so. We concluded that there was not” (Health and Wellbeing Committee July 2008).

5.2.4 Whether Wales goes alone or in partnership with the UK to introduce a system of opt out, national boundaries will play no part in the availability of organs. Organs, from wherever they are donated in the UK, will continue to be distributed throughout the UK on the basis of clinical need.

6 CONCLUSION

The time has come for a change in our attitudes to organ donation in the United Kingdom. Despite decades of campaigning only 28% of people have joined the organ donor register in the UK – yet study after study shows that most people would wish to donate their organs.

International experience shows that the most effective way to increase the number of organs donated is to move to an opt out system of organ donation. A position supported by most clinicians and the public. This change must be accompanied by improving the infrastructure needed to deliver more transplants.

The reality is that people in the UK are dying, at a rate of 3 per day. This switch will save lives. Wales has moved first, now we thrown down the gauntlet to the rest of the UK to follow suit.

ABOUT THE KIDNEY WALES FOUNDATION

Established in 1967, Kidney Wales has had over forty years of success in supporting and working with kidney patients in Wales. During this time the charity has supported many aspects of kidney patient care in Wales including transplantation, dialysis, research and patient welfare. Kidney Wales played a major role in getting an organ donor card attached to driving licences in the UK and was instrumental in setting up Lifeline Wales – a computer register of people willing to be organ donors in the event of their death.

In 2007 Kidney Wales launched the 'People Like Us' campaign, which put renal patients centre stage as they articulated their vision on how Wales could become a world class provider of renal services . With over 490 people waiting for a transplant in Wales, a chronic shortage of organs and increasing demand, People Like Us had three key suggestions for how to save lives:

- delivering a new dedicated transplant unit for Wales;
- working with partners to deliver a substantial increase in donors; and
- introducing legislation in Wales for Soft Opt Out presumed consent.

All three of these objectives have been met with positive responses from the Welsh Assembly Government and National Assembly for Wales.

The Kidney Wales Foundation also organises the organ donation campaign in Wales; working with six other charities and the British Medical Association to encourage more people to join the organ donor register.

Roy J. Thomas is the Executive Chairman of Kidney Wales Foundation and Chairman of Donate Wales Campaign. Roy was a lawyer for over 20 years who practiced in the private and public sector. This document has been prepared with a number of contributors including patients and supporters Alison Goldsworthy- Director of Communications of Kidney Wales, Felicity Waters (freelance consultant) and Daran Hill (Positif Politics) and Trustees of the charity. Our gratitude goes to everyone who supports saving lives of patients we support.

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