



Wheelchair Leadership Alliance: MPs Briefing Pack

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Introduction

The Wheelchair Leadership Alliance is a commitment group, focused on working with the whole system to exact positive and long lasting change in wheelchair services thereby addressing the current issues of waste, harm and delays and poor experiences of care [see Right Chair Right Time Right Now eDigest: <http://media.nhs.uk/edigest/>.]

To achieve this, a campaign entitled 'RIGHT CHAIR RIGHT TIME RIGHT NOW' will be launched on the morning of Monday 20th July 2015 in the form of a media photo-call in parliament square and subsequent national launch event in Speakers House, House of Parliament.

Launching at the same time is the Wheelchair Charter, a document that describes the key principles of excellence that wheelchair services should strive towards to ensure that wheelchair users get great experiences of care and the most positive outcomes. The Wheelchair Leadership Alliance is encouraging all to take action and to pledge their support to the Charter and Campaign, see <http://www.rightwheelchair.org.uk/areas-of-work/the-charter>,



Campaign overview

To effect change and ensure everyone gets the Right Chair Right Time Right Now the Wheelchair Leadership Alliance is launching a national campaign that will raise awareness of issues in wheelchair services and showcase how people's lives can be transformed with the right chair.

The campaign will:

- Raise awareness of widespread weaknesses in delivery of wheelchair services to build a commitment for change
- Be the driving force behind delivery of lasting and transformational change
- Share the vision of what a brighter future will offer and look like for wheelchair users
- Show what good practice already looks like and what can be achieved

The campaign will target two key audiences:

- Those that have the power to deliver change (e.g. commissioners, providers manufacturers)
- Those who can demand change (e.g. wheelchair users, carers and their families)

The alliance will provide all the relevant tools, resources and guidance to help everyone to get involved and raise awareness of the issues through their dedicated website

<http://www.rightwheelchair.org.uk>

The campaign is underpinned by a Wheelchair Charter which outlines the key principles that are crucial for the commissioning and delivery of high quality wheelchair services that will help people who use wheelchairs to live their lives to their fullest potential.

An important objective of the campaign is to encourage all who are involved or touched by wheelchair services, including Clinical Commissioning Groups (CCGs), wheelchair service providers, manufacturers, professionals, users and carers to pledge support for the Charter, as together those in power can be compelled to commit to delivering against the charter principles.

Charter overview

The Alliance has developed a Wheelchair Charter following engagement with wheelchair users, carers, commissioners, providers, charities, manufacturers and other key stakeholders from inside and outside the health and social care system. This Charter sets out the ten key principles below that will support the delivery of excellent wheelchair services and improve the experience of care received by wheelchair users.



1. A person centred service that works in partnership with service users & their carers and makes the user/carer voice central to any design, innovation and service change
2. Equality of access and provision for all, irrespective of age or postcode and including essential user skills training as standard
3. Entry to the service via referral from an appropriately skilled professional. The time from referral to delivery will be at least within the constitutional right of 18 weeks with further substantial improvements by 2016/17 for all people using the service
4. Assessment for all wheelchairs and associated postural support within nationally mandated timescales and priorities, taking into account all aspects of individual needs including those of carers
5. Establishing regular reviews with the user/carer according to their individual needs
6. Prescriptions which take into account the current and future needs for all adults & children including those of carers
7. Delivery, maintenance and emergency backup provided to nationally mandated time scales
8. Innovative and flexible budgeting working with key partners to strengthen integration across health, social care, work and education, enabling the accommodation of individual needs, independence, health and wellbeing
9. Recruitment of qualified staff in respect of numbers and skills, with support for ongoing development and training
10. Supporting clinicians, manufacturers and independent organisations working together to develop innovative, affordable products & solutions.

Desired outcomes

The overall goal is for every wheelchair user to receive a high standard of service, which sees them get the right chair for their needs in a timely fashion. Success criteria include, but are not limited to:

- Reduced waiting times for wheelchair users
- Wheelchair users getting the Right Chair for their needs first time
- The quality of wheelchair services and user experience across the country is of the same standard



Key facts & figures

- There are around 1.2 million wheelchair users in England, roughly 2 per cent of the UK population
- Wheelchair users with muscle wasting conditions often face severe delays to receive their chair:
 - 70% wait more than three months
 - 30% face a delay of more than six months
 - 15% wait more than 12 months
 - Unfortunately it is a very similar story for all wheelchair users
- For every 182 wheelchair users not able to work, the benefits bill can increase by up to £1m
- The positive economic contribution made when wheelchair users are in work can be up to £4.7m

For more detailed information see:

- *Right Chair Right Time Right Now eDigest:*
<http://media.nhsig.nhs.uk/edigest/>
- *Keeping the Wheels Turning: A research project investigating the needs of carers supporting people who use wheelchairs*
http://www.pamis.org.uk/cms/files/wheels_turning_report_with_cover_final_28april11.pdf
- *Get Moving 2013: The case for effective Wheelchair Services*
http://www.muscular-dystrophy.org/assets/0004/6094/Get_Moving_2013.pdf
- *SCHOOL WHEN YOU ARE ON WHEELS*
Young Wheelchair Users in Wales: A Snapshot of Challenges and Experiences in Education
http://www.cafamily.org.uk/media/439145/school_when_you_re_on_wheels.pdf

Alliance members

Baroness Tanni Grey-Thompson - Chair of the Wheelchair Leadership Alliance



Considered to be one of the most successful disabled athletes in the UK, Tanni has represented Great Britain at five Paralympic Games (Seoul, 1988; Barcelona, 1992; Atlanta, 1996; Sydney, 2000; and Athens, 2004), winning 16 medals – 11 gold, four silvers and one bronze.

Today Tanni holds several notable positions, including director of UK Athletics and member of the London Marathon board, member of Transport for London chairing the Environment, Corporate and Planning Panel, member of the Surface Transport and Safety, Health and Environment Assurance Panels, and since 2010 a non-party political crossbench peer in the House of Lords.

Fiona Carey - Wheelchair User and Advocate



Fiona accidentally got involved in the NHS as a patient rep, locally, regionally and nationally. She is Co-Chair of the East of England Citizen Senate; a member of the Specialised Urology (Cancer) CRG, and works with NHS England on a number of initiatives. She has helped to design and develop NHS Citizen, chaired the Wheelchair Services Summit with David Nicholson, and is part of the Coalition for Collaborative Care.

She also plays wheelchair basketball, with the most enormous enthusiasm.

Dr Jean Waters - Wheelchair User and Advocate



Jean spent 27 years in the NHS as a doctor, with 17 years as Consultant Anaesthetist at Gloucestershire NHS Foundation Trust. Since retiring, she has represented the voice of disabled people at local, regional and national level, including being a trustee and vice-chair of the Motor Neurone Disease Association.

Jean is currently patient representative on the neuroscience clinical reference group for NHS England, as well as chairing the Gloucestershire branch of the MND Association, serving as a trustee for the disability charity -The Barnwood Trust and vice chair of the Gloucestershire Neurological Alliance.

Kevan Baker OBE- Wheelchair User and voluntary Chief Executive of SPINE



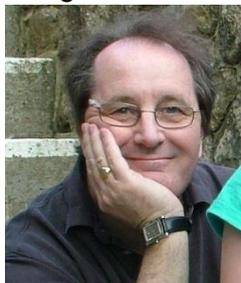
Kevan competed in Wheelchair Discus at four Paralympic Games, medalling in three. He has also been a former World Champion and four times World Record Holder. In 1994, he became Chairman of British Wheelchair Athletics and then in 1995 Vice Chairman of WheelPower, the British Wheelchair Sports Foundation, becoming

Chairman the following year.

In 2011 he was made an OBE in the New Year Honours List for voluntary services to disability sports.

Doug Morris - Carer and National Network of Parent Carer Forums (NNPCF) representative

Doug is carer for his son Ben, who was born in November 2000, and has Spinal Muscular Atrophy (SMA).



He has been involved in Parent Participation since joining the Swindon Parents and Carers Group shortly after it was set up in 2008. Having been involved in the Aiming High initiative from an early stage, Doug worked at developing parent participation in Swindon.

In addition to his NNPCF role, Doug is also on the board of trustees for the charity Together for Short Lives as a parent representative.

Krystyn Jarvis - Chair of the National Wheelchair Managers Forum, Manager of Shropshire Wheelchair and Posture Service and Occupational Therapist



Krys has been the Wheelchair Service Manager in Shropshire for 20 years. In that time she has been Chair of the West Midlands Wheelchair Managers Group for 10 years and was voted into her current role as Chair of the National Wheelchair Managers Forum (NWMF) in 2011.

Over these years Krys has been actively involved in all aspects of national service improvement which included the development of the Healthcare Standards for NHS-Commissioned Wheelchair Services produced by the NWMF, and the recent publication of the Wheelchair Therapist Competencies which have resulted in her being co-opted onto the Education & Training Committee of the Posture & Mobility Group, to jointly develop training to support these competencies.

Krys is an Occupational Therapist by profession and carries out clinical work as part of her role in Shropshire, which gives her first-hand experience of issues raised by users and clinicians. Previous to her specialism in the wheelchair field, she worked as an Occupational Therapist in acute hospitals, private hospitals and Social Services so gaining a wide body of experience and knowledge of disability issues.

Dr Caron Morton - Clinical Commissioning Group (CCG) Champions Network and GP



Dr Morton graduated in medicine at the Stellenbosh University, South Africa, in 1996 and came to the UK in 1997. She became a GP and partner at Station Drive Surgery in Ludlow in 2002.

She went into management in 2005 as Clinical Governance Lead and then Clinical Director for Practice Based Commissioning at Shropshire County Primary Care Trust (PCT) in 2009. Between 2010 and April 2011 she held the roles of PEC (Professional Executive Committee) Chair/Medical Director for Shropshire County

PCT and Acting Director of Quality and Safety across NHS Telford and Wrekin and Shropshire County PCT.



Dr Morton has been Chair of Shropshire CCG since April 2011 and was appointed Accountable Officer (Designate) in June 2012. Caron was formally appointed as Accountable Officer of the CCG in January 2013. In 2015 Dr Morton was awarded an MBE for services to primary care.

Raymond Hodgkinson MBE - Director of Public Affairs, British Healthcare Trades Association (BHTA)



Ray has worked in the healthcare industry since 1960 and ran his own business in the pressure care sector for twenty two years. He has many years of experience as a UK expert in international standards work for pressure care and seating products. He also serves as a Trustee of the Foundation for Assistive Technology.

Ray became BHTA's Director of Public Affairs in March 2015, having previously been Director General since 1999. He has overseen a dramatic decade of positive progress for the Association and its membership, championing the commercial interests of the membership at UK governmental, European and global levels.

In 2010 he was awarded an MBE for services to the healthcare industry.

Gail Russell - Independent Occupational Therapist and Posture Mobility Group (PMG) Representative



Gail graduated in Occupational Therapy from the University of Liverpool in 1994. She started working within the field of posture and mobility in 1998, and her last role within the NHS was Clinical Manager at Stockport Wheelchair Service. Gail has since gained a Post Graduate Certificate in Posture Management and is currently studying for an MSc in Skin Integrity and Treatment Skills at the University of Hertfordshire.

She now works as an independent practitioner in posture and mobility, provides education and training, as well as working as an Expert Witness. .

Angela Green - Yorkshire and Humber Improvement Academy and Physiotherapist



Angela is an Improvement Programme Manager within the Improvement Academy. She leads the Yorkshire & Humber Responsive Wheelchair Services programme and also supports the improving patient safety programme.

She previously worked for South Yorkshire CLAHRC and has worked in various settings of the NHS for 25 years as a physiotherapist, specialising in respiratory disease. Angela completed an MPhil in 2005 (Domiciliary Activity Monitoring in stable COPD) at University of Liverpool.

Karen Pearce – Director of Care, Motor Neurone Disease Association (MND)



Karen qualified as a chartered physiotherapist in 1978 and worked in the National Health Service in a variety of clinical and managerial roles for nearly 30 years. For five of these she had the privilege of working solely with people with MND, while managing services across the community and acute hospital settings.

Karen has worked for MND for 5 years, and has a special interest in equipment provision to improve quality of life and social inclusion.

Nick Goldup – NHS Partnerships Director, Whizz-Kidz



Nick joined Whizz-Kidz as NHS Partnerships Director in November 2011 following four years of pro bono support from his role as a European Buying Manager for Tesco. Nick has worked in a variety of blue chip procurement roles over a 17 year period including buyer for the DLR City Airport extension, BAA Pavement Team, Mitsubishi Electric Europe and over three and a half years as a timber buyer based in Jakarta, Indonesia.

Nick is working to streamline the charity's procurement activities, to help implement a number of innovations to support wheelchair users in the UK including the Child-in-a-Chair-in-a-Day model and to increase NHS partnerships for wheelchair provision.

During his spare time Nick is a keen triathlete, cyclist and marathon runner and has recently cycled from Lands' End to John O'Groats as part of a team raising £250k for Whizz-Kidz.

Tanvi Vyas - Muscular Dystrophy Campaign and Wheelchair User

Tanvi Vyas is a disability rights advocate, working with the *Trailblazers* young campaigners' network which is part of Muscular Dystrophy UK. She is also a member of DPTAC, the Department for Transport's Disabled Peoples Transport advisory committee.



She uses a powered wheelchair due to a neuromuscular condition.



Background information

Concerted efforts to improve wheelchair services across England were initiated as a result of a change day pledge in 2014 by former NHS Chief Executive Sir David Nicholson. Sir David committed to bringing wheelchair users together with NHS clinicians and managers, and with third sector organisations, in order to help address some of the intractable issues that need to be resolved to improve wheelchair services.

Consequently a Wheelchair Summit, held on 25 February 2014, brought these groups together to look at the problems with current wheelchair services and to identify what should happen locally and nationally to improve services.

A second wheelchair summit was held on 27 November 2014 to share progress to date from the improvement effort, engage more widely with key stakeholders and to collectively agree what else needed to happen to support the improvement effort. As a result consensus was reached to establish a national Wheelchair Leadership Alliance (supported by NHS England and NHS Improving Quality) as a task and finish national group working across England to take forward the agreed work stemming from the second Wheelchair Summit.

The overarching aim is to take action to transform the quality and effectiveness of services for people who use wheelchairs.



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