



# The LincPIN

The **Lincolnshire Post-Polio Information Newsletter**  
Volume 6 - Issue 10 — October 2009

WebSite - <http://www.lincolnshirepostpolio.org.uk>

Patient UK  
PatientPlus  
Article

Post-polio Syndrome

see inside



N.B. All mail including membership fees [except USA \$ checks] to PO Box 954, Lincoln, LN5 5ER, UK.



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## DONATIONS JUNE TO OCTOBER 2009

£ 1093.50 and US \$600.00

We would like to say a big thank-you to  
Dr. G Reed, Joan Deans, Simon Parritt, Jenny Raynor, Stuart Tanfield,  
M Pearson, Sandy Yarrow, Joy Witheridge, Ann Telford, Jenny Paulger,  
Mrs. J. Curtis, Mrs. A. Stone, Mrs. A. Devine, John De'Ath, Pauline Dunham, Mrs.  
J. Shaw, Ms. J. Dobbie, Barry Branston, Jennifer McGowan, and Robert Price  
And an unknown J. Sainsbury employee who nominated our Charity.  
who have rallied round to help us increase our funds with this fantastic sum.

Plus we would like to thank all our Committee and Operations Team  
who work so hard for us for their time, energy and financial savings  
donated to the LPPN from their PPS lives.

### Basic contact info reduced for this issue to save costs

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### NEXT LincPIN CHRISTMAS 2009

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### **Message from Jim Pullin, Acting Chair.**

On behalf of the previous and current Trustees: I would like to apologise for the hiccup in that the AGM on 3rd October 2009 was not quorate.

You will see from the enclosed letter that we have taken advice and scheduled an Extraordinary General Meeting for Saturday November 28th 2009. This will be in place of this year's Annual General Meeting. I do hope that those of you that are able will join us. Full details will be included with the next LincPIN.

I am delighted to announce that two new members have offered their extensive knowledge and experience to join the current Acting Management Committee and will be presenting information for discussion on the options available for us to move forward at the EGM.

You will find papers, including details of all nominations and a voting slip, enclosed with this LincPIN. I would be grateful if you could respond so that we receive the information by Friday 27th November 2009 [bearing in mind there could be a delay due to the current Postal Strikes].

We have had more than one request for the Annual General Meeting to be held in the summer months and will fix a date and venue for early July 2010 in the near future.

### **Membership Renewals and Information.**

Please note that all mail including membership fees should now be sent to the main LPPN address, PO Box 954, Lincoln, LN5 5ER. [exception are USA \$ checks which should be sent to LPPN c/o 4212 Blanding Blvd, Jacksonville, FL 32210, U.S.A.]

Renewal forms have been sent out with the newsletter in the past and due to the delay in sending out this LincPIN we now have 30 members due to renew. Do please note that if you pay yearly you can do this by Standing Order which will save the LPPN time and money. Renewal and Standing Order Forms have been enclosed for all members who have not paid so far this year.

**This LincPIN** - Only includes basic contact information on page 2 for this issue only. I must thank member Zsuzsannah Snarey, who is a Chiroprapist for doing us an article on How to look after our feet. We are also pleased to announce that with permission we can print the newly rewritten Patient UK PatientPlus article on Post Polio Syndrome which references some of our work. Do let us know if this helps you with discussions with health professionals.

### **The Big Care Debate**

If you are on our members email discussion list you will already have information on this and hopefully will have sent the Care and Support Team your views. If not then you might have seen information in the local press or even attended an event in your locality. Because this is such a hot potato for many of us already over 65 or approaching that age we believe it is essential that you read more about this and let them know what you think. If you want to then send us a copy as well.

**[jim.pullin@lincolnshirepostpolio.org.uk](mailto:jim.pullin@lincolnshirepostpolio.org.uk)**

## **How to look after your feet - advice from a chiropodist**

### **By member Zsuzsannah Snarey.**

Feet are the most distinctly human part of our anatomy. There are no other mammals in the animal kingdom with limbs that look like our feet. You might recognise people by their faces, but I as a chiropodist will recognise people by their feet. Everyone's feet are quite different from anyone else's. It is very important to look after your feet because you only ever get one pair. (Although I have heard that there are second hand shops!)

Your toes need to have enough space to move in, so don't buy shoes that will press toes close together otherwise corns may appear. Make sure that your shoes fit well and preferably made of leather so that any perspiration can easily evaporate. It is also a good idea to have shoes that are comfortably padded. Here may I recommend the shoes that I wear, they are made by Hotter. They can be ordered by phone or on the internet and delivered on a trial basis and if you are not happy with them they are collected by courier free of charge. They also have a very helpful advisory service by free phone.

Good hygiene is most important. You may wash your hands several times a day, and clean your teeth morning and night, but how often do you wash your feet? Once a day is recommended, using a mild soap or detergent and don't forget to dry them thoroughly especially between the toes. Don't share towels with others. Some people like to walk bare foot which is fine in a clean house but careful washing of feet is even more important. There are many microbes which are waiting to invade, and not everyone will remove their shoes when they enter your house. Just think what they might have walked through before they arrived!

You should change your socks or tights daily. They will be washed but you cannot wash shoes. They need to be allowed to dry out for at least 24 hours after wearing. Since you cannot put shoes in the washing machine, one way of killing possible germs and fungi that could be lurking inside is placing them in a large plastic bag, such as a bin liner and placing next to them a small open jam jar of cider vinegar. Close the bag and place it in a safe corner for 48 hours. As the cider vinegar evaporates it will fumigate the nooks and crannies of the shoes, but will not damage them.

Smelly feet are a sign of the fungi and bacteria that live on them. Some maybe fairly harmless but there are some that are very difficult to get rid of and cause trouble.

Athlete's foot is a fungal infection of the skin which is not restricted to athletes, it can be picked up from dirty swimming pool floors (always wear flip flops or "Crocks" there, which also stops you picking up the virus that causes verrucas), hotel rooms, gyms, gardens or even from your own carpet. This fungus likes warm, damp, dark places such as shoes, Wellingtons, old slippers and especially trainers which can get sweaty. You might notice itchy, painful, soggy areas between toes with split skin but it can also appear as dry, scaly skin on the soles of the feet. This dry form can be treated with an antifungal cream, and there is a very good spray for the condition in between toes. You can also apply surgical spirit between the toes to dry the skin. It might sting a bit, but it will dry the skin and discourage fungus growth. Don't use antifungal powder between toes, as it could irritate the skin, but it is fine to dust

inside the shoes or trainers. You need to be vigilant, because even if the condition seemed to have been eradicated, it can return if the hygiene measures are relaxed.

If athlete's foot is left untreated it can attack nails and then it is called fungal nail infection. In its mild form it can look like white streaks or patches on top of the nail which sometimes may be filed away. The fungus can attack the nail from the grooves at the side where it is difficult to clean, or under the nail if it is left too long. In severe cases fungal nail infection will look yellow or brown and stop the nail from growing; instead it becomes thicker and more difficult to cut. It eventually destroys the nail completely. Fungal nail infection can enter when the nail is damaged. An injury allows the fungus to creep in and multiply under the nail. It is a very common condition, not restricted to the elderly. In severe cases oral medication is needed from the GP and a chiropodist needs to remove the damaged areas of nail which are probably not attached to the skin, so this is a completely painless procedure. The oral medication can sometimes have side effects and if you have other medication for other conditions, your GP may not prescribe it. Your GP can prescribe a broad-spectrum anti-fungal medication to eliminate the fungus if local treatment or your prevention regime has failed.

Fungal infection of the skin and nails is often not taken seriously, yet ring worm, another fungal infection of the skin would be treated by the GP. For patients with diabetes it is important to treat any infection.

Other problems that may take you to see a chiropodist would be ingrowing toenails which may be due to ill fitting shoes, incorrect nail cutting or a hereditary condition. It happens when the nail pierces the skin and bacteria enter and it is extremely painful.

Zsuzsanna Snarey <zsuzsi.snarey@googlemail.com

### **A FEW ITEMS TO HOPEFULLY MAKE YOU SMILE.**

- A newscaster interrupted scheduled programming to announce the outcome of the states interagency planning committee aimed at solving handicap drivers parking dilemmas. "More on handicap drivers at 10 P.M.," he said.

My ten-year-old granddaughter Andie looked at me in disbelief. "I didn't know they could call handicapped drivers 'morons' on national television!" she remarked.

- Dwarf statistics - Statistically, 6 out of 7 dwarves aren't happy.
- NURSING HOME OFFER - A little old lady was running up and down the halls in a nursing home. As she walked, she would flip up the hem of her nightgown and say "Supersex." She walked up to an elderly man in a wheelchair. Flipping her gown at him, she said, "Supersex."

He sat silently for a moment or two and finally answered, "I'll take the soup."

- Police arrested two kids yesterday, one was drinking battery acid, the other was eating fireworks.

They charged one and let the other one off.

- What happened when a frustrated homeowner stuck his garden hose into one of the numerous mounds in his backyard? He made a fountain out of a molehill.

## **Patient UK PatientPlus Article on Post Polio Syndrome**

PatientPlus is an extension to Patient UK, covering a wide range of medical subjects in more detail. The articles are written for doctors and other healthcare professionals. However, some people find that they add depth to the 'plain English' articles found in the patient focused sections of this website which are specifically written for non medical people.

PatientPlus information is written by our expert authoring team, consisting of independent GPs, doctors working for producers of GP further education courses, and occasionally reproduced with permission from national organisations such as the British Heart Foundation

### **POST POLIO SYNDROME**

Post-polio syndrome (PPS) is the onset of new deterioration in function that may occur many years after recovery from acute poliomyelitis. PPS comprises various possible symptoms such as fatigue, weakness, joint and muscle pain, reduced respiratory function or dysphagia. PPS does not necessarily imply progressive deterioration, and can be helped by treatment. Management requires careful assessment and a multidisciplinary approach.

#### **Definition/diagnosis**

Suggested criteria for diagnosis of PPS are: [1]

Previous history of poliomyelitis.

Stable period after recovery (usually >15 years).

New symptoms, such as generalised fatigue, new weakness, abnormal muscle fatigue and muscle atrophy.

Exclusion of other cause of muscle weakness (but note that problems can be multifactorial [2] as discussed below).

#### **Note:**

There is no universal definition of PPS, but most sources use one similar to the above.

Some experts suggest that PPS may be diagnosed in those where there is no clear history of paralytic polio, but where the past history or investigations suggest that previous polio is likely. [3]

#### **Aetiology [2]**

There is NO reactivation of the polio virus infection (patients may need reassurance about this).

The exact cause of PPS is unknown:

There may be new muscle atrophy and weakness relating to changes in motor neurones.

Overuse or disuse of muscles play an important role. [4]

The cause of PPS symptoms may be multifactorial. For example, disabilities resulting from acute polio, combined with activities of daily living, can produce large stresses acting on abnormal muscles and joints. This may lead to other problems which contribute to PPS, such as:

Joint deformities

Osteoporosis  
Scoliosis  
Cervical spondylosis  
Peripheral nerve entrapment (can occur with callipers, crutches etc.)

### **Epidemiology [4]**

It is estimated that PPS may occur in 28 - 75% of patients with previous polio.  
The time interval is usually around 35 years, but may be 8 - 70 years after the acute polio episode.

### **Presentation**

Common symptoms are: [4]

Generalised fatigue  
Joint and muscle pain  
New muscle or joint weakness  
Muscle atrophy  
Cold intolerance  
Bulbar symptoms - speech, swallowing or respiratory symptoms  
Worsening respiratory function - may present as headaches, fatigue or sleep disorder (see below under 'Respiratory and sleep problems in post-polio syndrome').

Any of these can lead to a deterioration in day-to-day functioning. A small change in clinical terms can mean a large one in its effects on daily living.

### **Assessment**

Listen to the patient's story.

The most important question to ask is not "can you do this activity?", e.g. climbing stairs, but "how do you do it?" This can reveal the functional change, e.g. stopping to rest half way, going upstairs by shifting on their bottom. [5]

A patient questionnaire such as "My Polio Life" can be useful. [6]

Multidisciplinary assessment may be needed, e.g. involving physiotherapist, occupational therapist, neurologist, orthopaedic/orthotic team and respiratory physician.

Bear in mind that various factors can make assessment more difficult: [7]

Polio survivors are used to coping and adapting. Hence the importance of asking - and observing - how patients carry out each activity.

Symptoms can vary from day to day and can be affected by recent activity, overuse or rest.

Patients may deliberately allow for a stressful hospital visit day by resting beforehand. This can give a falsely good picture. Ask what symptoms are like "on bad days".

Results can appear normal if patients are given long rests between tests, or if only the best result is recorded.

Respiratory and sleep problems are easily missed (see below under 'Respiratory and sleep problems in post-polio syndrome').

Anecdotally, patients with PPS have had their symptoms dismissed after apparently normal or near-normal results of tests, such as lung function or muscle power.

## **Investigations**

These will depend on symptoms, but could include:

Muscle tests - but be aware that simple tests of isometric muscle strength may be insensitive, [5] [8]

Respiratory investigations (see below under 'Assessment of respiratory problems')

Sleep studies (see below under 'Assessment of respiratory problems')

Swallowing studies, e.g. barium swallow

Investigations to exclude other causes

## **Differential diagnosis [1]**

Other causes of fatigue or weakness, e.g:

Other types of neuropathy or myopathy

Multiple sclerosis

Amyotrophic lateral sclerosis or other anterior horn cell diseases

Myasthenia gravis

Systemic conditions, e.g. anaemia, chronic infection, hypothyroidism, collagen disorders, medication side-effects

Other causes of pain, e.g:

Arthritis, bursitis, tendinitis

Myalgias - polymyalgia rheumatica, fibromyalgia

Neuropathies

## **Management [2]**

A multidisciplinary approach is helpful. [9] Some important aspects of management are:

The correct balance of rest and exercise is essential:[4,10]

Avoid overuse, as too much exercise causes increased weakness and fatigue in damaged muscles.

Graded exercise is beneficial - this should probably be broken up by periods of rest.

Non-swimming exercise in warm water often helps.

Many polio survivors are used to leading active lives and, to some extent, ignoring their disability. Adapting to PPS and the need for more rest may require lifestyle and employment changes.

[11]

Orthopaedic and orthotic management of skeletal problems, e.g:

Simple supports for knee, ankle and cervical spine can improve function.

Replace damaged aids.

Muscle pain:

Physical treatments, such as warmth/cold, massage, passive stretching.

Transcutaneous nerve stimulation.

Acupuncture.

Anaesthesia requires special considerations. [12]

Nutrition:

Good nutrition and weight control.

Some patients find that a high protein diet is helpful (e.g. the post-polio institute "hypoglycaemia diet"). [11]

Specific treatment of other problems, e.g. dysphagia and respiratory and sleep problems (see below under 'Respiratory and sleep problems in post-polio syndrome').

## **Respiratory and sleep problems in post-polio syndrome [13,14,15]**

### **Importance**

Respiratory problems in PPS are an important cause of symptoms and complications, including sleep disorders.

They may be under-diagnosed or inadequately assessed.

Treatment can improve both quality of life and prognosis.

### **Aetiology [14]**

Respiratory problems in PPS may be due to one or more of:

Respiratory muscle weakness.

Bulbar impairment - this may affect control of the upper airway or the respiratory cycle. If the upper airway is affected, there may be obstructive sleep apnoea.

Skeletal deformity - scoliosis or chest wall stiffness.

Other pathology, e.g. COPD, asthma, obesity.

Aspiration - if swallowing affected.

All these are likely to worsen during sleep. The pattern of respiratory impairment may be hypoventilation, obstructive sleep apnoea, or both.[16]

### **Symptoms**

Respiratory failure can develop insidiously - symptoms may be subtle or unnoticed. Breathlessness may not be a symptom in patients with limited mobility. Possible symptoms are:

Sleep disruption, eventually leading to insomnia, daytime sleepiness or fatigue.

Morning headaches, irritability, poor concentration, anxiety or depression.

Abnormal sleep movements, nocturnal confusion, vivid dreams.

Breathlessness may be positional.  
Weak cough, chest infections.

## Signs

May be subtle - possible signs are:

Unexplained tachypnoea.

Use of accessory muscles.

Abdominal paradox - this is inward movement of the abdomen on inspiration while the upper chest expands.

May be best seen with patient supine during a sniff manoeuvre.

When upright, can be missed as the diaphragm passively descends at the beginning of inspiration.

Severe, untreated nocturnal hypoxaemia can cause pulmonary hypertension, giving signs such as raised JVP and ankle oedema.

## Assessment of respiratory problems

Listen to the patient's story and preferences.

Assess:

Voice and cough

Chest deformity

Observe patients in realistic situations, e.g. doing repeated tests or actions, and doing everyday actions in which they may be using the necessary breathing muscles to achieve another task

Investigations:

Peak flow and cough peak flow

Spirometry

Both seated AND supine spirometry are needed

A sensitive indicator of respiratory muscle weakness is reduction in maximal inspiratory pressure

Oximetry (and possibly capnography)

Sleep study (polysomnogram)

ECG and chest X-ray if appropriate

Full sets of lung function tests and arterial blood gases may not be helpful in this scenario, unless intrinsic lung disease is suspected.

## Management of respiratory problems

There are various options - choice will depend on the patient's individual situation and preferences. Night-time mechanical ventilation is often used. This helps by resting the respiratory muscles at night, and preventing deterioration of respiratory function during sleep. It also treats the secondary sleep disorder.

Supportive measures include:

Not smoking

Avoiding sedatives and alcohol

Optimal weight and nutrition

Pneumococcal and influenza vaccination  
Postural support if needed  
Prompt treatment of chest infections  
Techniques such as assisted cough or glossopharyngeal breathing ('frog breathing')  
Chest expansion exercises

Assisted breathing options are:

Non-invasive intermittent positive pressure ventilation (NIV or NPPV) is often useful - see box below.

Rocking bed:

This helps breathing by rocking a patient consecutively head up and head down. It is surprisingly effective, especially where muscle weakness is mainly diaphragmatic

Pneumobelt:

This gives intermittent abdominal pressure ventilation and is useful for daytime assistance

Negative pressure ventilation:

Examples are tank ventilators (iron lung), jacket ventilators (Tunncliffe), and cuirass ventilators. The devices are cumbersome, and mainly used where NIV is not tolerated, or to provide 'respite' from NIV

Tracheostomy ventilation.

### **Non-invasive ventilation and 'bi-levels' explained, [13,14]**

NIV increases alveolar ventilation. It is provided by a portable ventilator and a tightly-fitting nasal or facial mask or nasal "pillow".

Note: NIV is NOT the same as continuous positive airway pressure (CPAP). CPAP is useful for obstructive sleep apnoea because it maintains the upper airway. It is not normally indicated for hypoventilation from respiratory muscle weakness

People with neuromuscular disease may have difficulty breathing in, so require NIV with higher inspiratory than expiratory pressures. This can be provided using a 'bi-level' ventilator:

Bi-level ventilators developed by modifying CPAP. The inspiratory positive airway pressure (IPAP) and expiratory positive airway pressure (EPAP) settings are adjusted separately.

The difference between IPAP and EPAP is called the span.

For example, a patient may require an IPAP of 14 and an EPAP of 3.

Sensitive flow triggers enable normal breathing to be supported. There may be a back-up control to provide ventilation if respiratory effort fails to trigger a breath.

## Prognosis

Experience suggests that the functional deterioration does not necessarily progress.

Fatigue and reduction in mobility may stabilise or progress very slowly.

## Prevention

Prevention of acute polio infection is discussed elsewhere (see separate article on Poliomyelitis).

Prevention of PPS is not much discussed in the literature. Given the various known contributing factors, it seems possible that PPS problems might be reduced by:

Careful management of exercise and daily living activities to optimise muscle and joint use, and prevent overuse or disuse.

Correct maintenance of aids and prostheses.

Monitoring and early treatment of associated/contributing problems such as:

Osteoporosis.

Obesity.

Respiratory problems.

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### **Internet and further reading**

Lincolnshire Post-Polio Network. Post-polio information service for patients and health professionals.  
[www.lincolnshirepostpolio.org.uk](http://www.lincolnshirepostpolio.org.uk)

The Lincolnshire Post-Polio Network Library  
<http://www.ott.zynet.co.uk/polio/lincolnshire/library.html>

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©EMIS 2009. as distributed at <http://www.patient.co.uk/doctor/Post-Polio-Syndrome.htm>, used with permission."

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# Shaping the Future of Care Together

The Government is working to create a new National Care Service for England that is fair, simple and affordable. How should it be structured and paid for? Tell us what you think of the options for reform. This is the Big Care Debate.

**[Editors note** - This is a very complex document and we have limited space in the LincPIN. We follow this with a short background statement. The forward by the Secretaries of State. David Behan is the Director General of Social Care at the Department of Health and writes regular statements. We include an excerpt from a statement he made on September 25th 2009 and his full statement from 22nd October 2009. We follow this with the text from the On-line version of how you can have your say. At the very end of the article we give you full details of how to obtain more information, how to give your views online by email or by post.]

**Background.** Polio Survivors were not expecting PPS and many members have had to give up work early on medical grounds and report the nightmare of applying for Incapacity Benefit and DLA. In the last few years help from Social Services to manage in your home has changed from direct provision [staff coming into your home] to direct payments and individual budgets [awarding you an amount of money to purchase your own care]. One statement made at a recent meeting with Social Services says it all 'I used to be registered disabled, now I am registered as an employer and have to spend many hours each week completing all the necessary paperwork for the Inland Revenue and Social Services' Medical and Needs assessments have been and are still failing our members on a daily basis with many reporting the continual stress of dealing with all this detrimental to our health. At the moment we have control over the DLA and Attendance Allowance awarded to us. Of huge concern is the suggestion that the Care component of DLA and Attendance Allowance may be taken away from those 65 and over and given to Social Services to pay for our care in the future. It is imperative that we [and our families] read more about this and we make our views known.

## **Foreword: Secretaries of State**

### **A new vision for care and support**

This Green Paper sets out a vision for a new care and support system. As we all know, more and more of us are living longer which is a good thing, but more of us will also live with needs for care and support. The current care and support system was designed in the 1940s and we need to develop a system that fits our needs in the 21st century. We need a system that is fairer, simpler and more affordable for everyone. To build this, we will need to make some big decisions and reach agreement across society on the right way forward for England. So, this is the beginning of a Big Care Debate.

### **The case for change**

Our society is going through dramatic change. We are living longer and leading more active lives, and we expect our public services to allow us to live our lives the way we want to. But this presents issues which public services need to address.

Care and support affects everybody. We may need care ourselves, know someone else who does or help pay for care and support through our taxes.

We know that, despite many improvements over the years, the system is still regarded as unfair. Many families who have saved all their lives find themselves facing high costs for

care and support for themselves or their loved ones.

We know that it will not be able to cope with future pressures in its current form and we need to reform the funding system.

### **A National Care Service**

Building on what people told us that they wanted from services during last year's engagement programme, this Green Paper sets out our vision to build a high-quality National Care Service that is fair, simple and affordable.

People want to be treated fairly. We want a system whereby people get the support that they need wherever they are in the country.

The system needs to be simple. People want to know exactly what to expect from the system and what they need to do in order to get help.

Care and support needs to be affordable for everyone. At the moment surveys tell us that more than half of people think that care will be free. But it is not. Care and support costs can be very high: a 65-year-old can expect to need care costing on average £30,000 during retirement.

People told us that everyone in society shares the responsibility for making sure that people receive the care they need, but the funding of care and support generated some of the most heated discussions in our engagement process. People were passionate that any new funding system should be fairer, proportionate to what people could afford and easy to understand.

This Green Paper outlines our vision for a National Care Service and what people should expect from it. It asks for your views on some difficult choices that we need to make for this vision to become a reality and to ensure that there is enough funding for the system to be able to deliver the kind of care and support that we, as a society, should be aspiring for. The proposals in this Green Paper would bring about some of the most fundamental reforms ever in care and support.

### **The Big Care Debate**

We are holding a public consultation until 13 November 2009 on the questions raised in this Green Paper.

These changes will affect any care that you and your family receive, so we want to know what you think. We invite you to join the Big Care Debate. Let's shape the future of care together.

The Rt Hon Andy Burnham MP	Secretary of State for Health
The Rt Hon Liam Byrne MP	Chief Secretary to the Treasury
The Rt Hon Yvette Cooper MP	Secretary of State for Work and Pensions
The Rt Hon Lord Mandelson	Secretary of State for Business, Innovation and Skills
The Rt Hon John Denham MP	Secretary of State for Communities and Local Government
The Rt Hon Tessa Jowell MP	Secretary of State for the Cabinet Office
The Rt Hon Ed Balls MP	Secretary of State for Children, Schools and Families

**David Behan is the Director General of Social Care at the Department of Health.** He writes regular updates on the latest news and developments.

### **Excerpt from 25th September 2009**

'Many of the responses we have received are passionate in their defence of the current system, spelling out how a large number of people rely on

Attendance Allowance and Disability Living Allowance to maintain their quality of life. We have also heard from a lot of working age people who are worried that their DLA will be taken away from them'

## **22nd October 2009**

The Secretary of State for Health has made it clear that Disability Living Allowance for the Under 65s will not be affected by Government plans to create a National Care Service.

Speaking at the National Children and Adult Services Conference in Harrogate, Andy Burnham MP said: "I am encouraged by the response to our Big Care Debate and welcome the fact that other political parties are beginning to put their ideas on the table. There are big differences between what we are saying but we are beginning to create what I wanted to see - unstoppable momentum for legislation in the next Parliament.

"But, while the debate is moving quickly, I do want to stress that the door is wide open for discussion. We are still in a consultation period. No decisions have been made on funding options. We are still listening – about funding, about structures, and about how to build a forward-looking system of care.

"One avenue I do want to close down, however, is the debate and controversy over Disability Living Allowance.

"We recognise that this is an important benefit for disabled people, and I can state categorically that we have now ruled out any suggestion that DLA for under-65s will be brought into the new National Care Service.

"This is because, whilst there will be increases in the numbers of disabled people of working age who need care, the majority of the people needing care in the future will be older people.

"However, we do think there may be a case for bringing together elements of some disability benefits, such as Attendance Allowance, with social care funding, to create a new care and support system to provide for the needs of older and disabled people.

"But the important principle is that people receiving any of the relevant benefits at the time of reform would continue to receive an equivalent level of support and protection under a new and better care and support system.

"And let's not forget, everyone - regardless of wealth or asset base – will benefit from the protection and peace of mind that the National Care Service will provide."

The Government is currently carrying out a consultation – the Big Care Debate - on the new National Care Service, a vision for which was set out in July's Green Paper Shaping the Future of Care Together.

### **Join the Big Care Debate and help shape the future of care and support**

The Government's new Green Paper Shaping the Future of Care Together sets out a vision for a National Care Service for all adults in England. A service that is fair, simple and affordable for everyone, underpinned by national rights and entitlements and personalised to individual needs. It asks for your views on some difficult choices that we need to make for this vision to become a reality. The proposals in this Green Paper are some of the most fundamental reforms ever in this area.

#### **Why do we need a debate**

We are an ageing society. For the first time ever there are more people over the age of 65

than there are under the age of 18. Life expectancy is going up and advances in medical science mean that people with a disability are living longer. This is worth celebrating but it does mean we need to radically change the way care and support is provided and paid for. The current system has its basis in the 1940s and there have been huge social changes in terms of what we value and what we want from public services. People now want more independence, choice and control, and we need to reflect these demands.

As a society we will have to spend more on care and support in the future. One of the most important issues we want your views on is what is fair to ask people to pay for themselves, and how we protect people from having to pay a huge bill if they need long-term residential care.

### **The process**

The Green Paper has been informed by a six-month engagement process that took place in 2008 in which thousands of people were asked about their views on the challenges that we face for the future and the problems with the current system.

### **The debate questions**

We'd like you to answer as many of these as you can, but don't worry if there are some you don't have a view on, just leave them out. When answering these questions you may want to consider any impact our proposals may have on race, disability, gender, sexual orientation, religion, belief or age equality for you or your service users.

## **1 The vision for the future**

We have suggested six key things that everyone should expect from a National Care Service and we want your views on them.

### **1a. Prevention services**

You will receive the right support to help you stay independent and well for as long as possible and to stop your care and support needs getting worse.

### **1b. National assessment**

Wherever you live in England, you will have the right to have your care and support needs assessed in the same way and you will have a right to have the same proportion of your costs paid for.

### **1c. A joined-up service**

All the services you need will work together smoothly, particularly when your needs are assessed. You will only need to have one assessment of your needs to access a whole range of care and support services.

### **1d. Information and advice**

If you need care and support, or you are preparing for it, you will find it easy to get information about who can help you, what care and support you can expect, and how quickly you can get it.

### **1e. Personalised care and support**

Your care and support will be designed and delivered around your individual needs. As part of your care and support plan, you will have much greater choice over how and where you receive support, and the possibility of controlling your own budget wherever appropriate.

## **1f. Fair funding**

Everyone who qualifies for care and support from the state will get some help meeting the cost of their care and support needs. Your money will be spent wisely to fund a care and support system that is fair and sustainable.

### **Consultation Question 1.**

**1a) Is there anything missing from this list - 1 (a to f)**

**1b) How should this work?**

## **2 Making the vision a reality**

We think that to deliver this vision three main changes are required to the care and support system.

1. More joined-up working between health, housing, social care and benefits systems.
2. A wider range of care and support services, so people have a greater range of services to choose from.
3. Better quality and innovation. Staff must have the right training and skills, and services should be based on the best and most recent information about what works well in providing care.

### **Consultation Question 2.**

**2a) Do you agree?**

**2b) What would this look like in practice?**

**2c) What are the barriers to making this happen?**

## **3 Funding care and support in the future**

We will achieve this vision by making better use of taxpayers' money so funding is focused on people who can benefit from it and need it most. But the money in the system at the moment won't pay for all of everyone's care in the future.

In deciding how to fund care and support, there are some very difficult decisions to make.

### **Funding options**

We have therefore proposed three options for funding a National Care Service.

**1. Partnership:** The responsibility for paying for care and support would be shared between the Government and the person who has care and support needs. The Government provides between a quarter and a third of the cost of care and support, more for people on a low income. Today's 65-year-olds will need care and support costing on average £30,000.

The Partnership system would work for adults of all ages. Under this system we expect many people born with a care and support need to qualify for free care, as

they do under the current system. Those working-age adults who do not qualify for free care (those who are better off) would have the same offer around funding as people over 65.

**2. Insurance:** The same as Partnership but the Government could help people prepare to meet the costs that they would have to pay for themselves through an insurance-based approach. As well as providing people with between a third and a quarter of the cost of care and support, the Government would make it easier for people to take out insurance to cover care and support costs if they want it. It is estimated that the cost of insurance could be around £20,000 to £25,000.

The Insurance part of the second option would be likely to be less relevant to people who have been born with a care and support need, since people cannot insure against the risk of something that has already happened. However, many people born with a care and support need are likely to qualify for free care under the Partnership element of the system.

**3. Comprehensive:** Everyone over retirement age who can afford it would pay into a state insurance scheme, so that everyone who needs care and support will receive it free. It is estimated that the cost of being in the system could be between £17,000 and £20,000.

The Comprehensive system would be for people over retirement age, but we would also look at having a free care and support system for people of working age alongside this.

#### **What about a system based on tax funding?**

We have ruled out a system based on tax funding, because it would put a large burden of paying for care and support on people who are working. Given demographic changes, there will be an increasing pressure on a shrinking proportion of working-age people. In 2007, the number of people aged over 65 became greater than the number of people under 18 for the first time. Because the majority of people benefiting from a reformed care and support system will be pensioners, it is fairer to think about more targeted ways of bringing in extra funding, rather than placing a lot of the burden of the system on people of working age.

#### **What about accommodation costs?**

It is important to note that these options consider only the cost of people's care and support. People entering a care home would have to pay for their accommodation costs, such as the costs of food and lodging. This is because the state would not pay for people to buy their food or pay their mortgage or rent if they were living at home.

### **Consultation Question 3a.**

3a) Which of the three funding options do you prefer?

1. Partnership,
2. Insurance,
3. Comprehensive.

Why is this your preference?

Of course, the state will always have a role in supporting people who are in a care home who cannot afford these costs.

### **A national or local system?**

We believe that the care and support system should be fair and universal. But we also need to ensure that the system is flexible enough to respond to local circumstances and encourage innovative approaches. There could be two different approaches to how the system works - either a part-national, part-local system or a fully national system. The two approaches have different implications for the way money is raised and distributed around England.

#### **Consultation Question 3b**

**3b) Should local government say how much money people get depending on the situation in their area, or should national government decide?**

If you want to learn more or run your own Big Care Debate and tell us about it, there are some materials that can help you and can be downloaded at [www.careandsupport.direct.gov.uk](http://www.careandsupport.direct.gov.uk)

**The Big Care Debate lasts until 13 November 2009.**

**The Green Paper - Shaping the Future of Care Together -**

**can be downloaded at**

<http://careandsupport.direct.gov.uk/greenpaper/the-green-paper-and-supporting-documents/>

**Or order a copy to be posted to you by**

**phoning 0300 123 1002**

**The Big Care Debate Questionnaire can be completed online at**

<http://careandsupport.direct.gov.uk/questionnaire/>

**Or you can give your views by email**

[careandsupport@dh.gsi.gov.uk](mailto:careandsupport@dh.gsi.gov.uk)

**Or Write to**

**Care and Support Team,**

**Room 149, Richmond House, 79 Whitehall, London SW1A 2NS**

**Remember Remember the 13th November**