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## News Release

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For immediate release

### **A Short Stay in Switzerland** **25<sup>th</sup> January 2009; BBC1, 9 – 10.30 pm**

Starring award winning actress Julie Walters as Dr Anne Turner, this moving docu-drama based on a true story, depicts the emotional turmoil the Turner family faced following Dr Turner's diagnosis with Progressive Supranuclear Palsy (PSP), a devastating terminal brain disease, and her shocking revelation that she intended to end her life by travelling to Switzerland for assisted suicide.

There is no effective treatment for PSP. Dr Turner knew she was destined to gradually lose her ability to walk, talk, eat, drink and see. She viewed this and the loss of her independence as unbearable. Her recent experience in caring for her late husband who died from a different but equally devastating brain disease undoubtedly coloured her view. Initially Dr Turner's children fought against her decision but came to realize they were powerless to do anything other than support their mother's wish to end her life.

Assisted suicide is the topic central to 'A Short Stay in Switzerland' and the drama is certain to re-ignite debate on the rights and wrongs of assisted suicide. However, for people with PSP, there are wider issues that require immediate action. There is much that could and should be done to make life better for people living with PSP thereby removing some of the fear and anxiety that drives individuals like Dr Turner to consider assisted suicide which results in the premature ending of their life.

Key issues for people with PSP include:

- The lack of awareness about PSP amongst the medical profession. At least three out of every four cases are misdiagnosed resulting in patients being given inappropriate treatments which exacerbate their condition and cause unnecessary anxiety and distress. Many cases of PSP go undiagnosed.

***There is a need for the medical profession to be better educated about PSP.***

- The lack of awareness amongst health and social care professionals about PSP and about the needs of people with PSP at different stages of the disease, resulting in a lack of appropriate care and support.

***There is a need for health and social care professionals to be better educated about PSP and about patients needs at the different stages of the disease.***

- The lack of provision of palliative care and the lack of availability of hospice beds for people with PSP.

***There is a need for government to increase investment in palliative care to ensure the availability of hospice beds for people with PSP.***

- The lack of investment in health and social care services for people with PSP.

***There is a need for government to ensure appropriate investment within the NHS to meet the health and social care needs of people with PSP***

- The lack of an effective treatment for PSP – to slow or halt its progression.

***There is a need for government to commit to fund research aimed at developing a treatment for PSP.***

Mrs Jane Hardy CEO of the PSP Association said:

“It is an absolute disgrace that for so long PSP has been ignored by the decision makers in our health and social care systems. Many medical and healthcare professions are not educated about PSP so misdiagnosis and non-diagnosis is rife. Likewise, health and social care professionals are not adequately educated about the needs of people with PSP at the different stages of the illness so patients do not get appropriate care and support and suffer unnecessarily. Moreover, there is a total failure to recognise the palliative care needs of people with PSP. It is no wonder that when faced with system failure of this magnitude, people like Dr Turner are tragically pushed to consider assisted suicide. What we need is a fundamental change in attitude to PSP by decision makers with a commitment to implement improvements to health and social care that will make a big difference to the quality of life of those living with PSP.”

Dr Angela Wilson, Director of Research at the PSP Association said:

‘People with PSP are desperate for a treatment. An effective treatment would completely revolutionise their world. Research is essential to develop a treatment but the UK government has funded no PSP research and virtually nothing has been funded by any of the major medical research funding bodies in the UK. This has to change. Research into PSP, like that for any other disease area, must be funded properly by government. Shouldering the financial burden for PSP research in the UK is too big a task for The PSP Association alone.’

The Lord Coe (Seb) who is a close supporter of the work of the PSP Association and one of its Vice Presidents said:

“Dr Anne Turner’s story is immensely sad. My own mother suffered from PSP from which she died in 2005 so I have first-hand experience of the disease. I have been working with the PSP Association since my late mother was diagnosed with PSP and am doing all that I can to raise awareness of PSP, to ensure that everyone living with PSP has access to the care and support they need, and that more research is undertaken so that we can get an effective treatment and hopefully a cure for this devastatingly cruel disease.

**- Ends -**

For general information about PSP and The PSP Association please call 01327 322410 or visit [www.pspeur.org](http://www.pspeur.org).

For press enquiries please call Dr Angela Wilson on 01327 322410 or on 0774 9795172.

## Notes to Editors:

- PSP (Progressive Supranuclear Palsy) is a devastating brain disease that progressively robs its victims of their ability to walk, talk, see, swallow, eat and drink. In the later stages of the disease patients are confined to a wheelchair or are bed-bound, unable to communicate with the world around them, yet remain mentally alert. On average patients die within seven years from the onset of the disease; however from diagnosis to death is usually between two and four years.
- PSP is one of the last really harmful diseases for which there is no effective treatment. The cause of PSP is unknown and it can strike anyone regardless of gender, race or social class although it tends to appear in the over forties. PSP is frequently misdiagnosed as dementia, stroke, or Parkinson's disease resulting in the wrong treatment which can exacerbate the disease and all too often goes undiagnosed in older people resulting in unnecessary suffering.
- PSP is thought to affect some 10,000 people in the UK but the actual number is likely to be much higher as it is often misdiagnosed and goes undiagnosed in the elderly. The number of cases of PSP is set to rise significantly with the changing demographics and an ageing population.
- The PSP Association was established as a registered charity by Brigadier Michael Koe, OBE and his wife Sara in 1994, shortly before she died from PSP in 1995. They were appalled to learn that so little was known about this disease and established the charity to conquer PSP through effective research, education, welfare and communication.
- Since The PSP Association was established in 1994 it has:
  - developed a unique UK-wide Nurse Specialist Service to support PSP patients and their carers.
  - helped over 3,000 families with members suffering from PSP
  - invested more than £2m into research into PSP.
  - established the Sara Koe PSP Research Centre, the first PSP research centre in the world, based at the Institute of Neurology, 1 Wakefield Street, London.
- PSP claimed the life of *Daily Mail* columnist Nigel Dempster in 2007, and talented actor and concert pianist Dudley Moore died from the disease in 2002.
- J.N.P. Watson, author and former polo correspondent for The Times, died from PSP in February 2008.
- Case studies are available for interview.

### *Working for a world free of PSP*

The PSP Association. Registered charity 1037087

**Patron:** HRH The Duchess of Gloucester GCVO **President:** General the Lord Guthrie of Craigiebank GCB,LVO, OBE  
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