



Workshop:

Ethical aspects of stem cell repositories and stem cell databases
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Brain diseases have become a major challenge for contemporary society. Several changes to society in the last three decades have had implications for people and their families living with chronic neurological conditions.

1. The change in the role of voluntary organisations highlighting the importance of listening to the needs of the patients and their families
2. Demographic changes resulting in the increase in the number of elderly frail people
3. Increasing number of the global population living with brain disorders
4. The need to focus more sharply on the ageing population affected by neurological disorders so that their needs can be met appropriately

There have been enormous shifts in patterns of care of chronic disease over the past few years. Our population is living longer, and with old age comes frailty and more evidence of long-term neurological conditions. Demographic changes mean that brain disorders are set to become more common with the rise in the number of elderly, putting even more pressure on carers. For years women have been the carers within the home but their role has evolved drastically in recent years. Many have excellent careers, resulting in changed family structures and a decreasing number of family carers.

To be able to focus accurately on treatment and management to improve quality of life we need to know what the patients need. They need to be referred to a doctor with a real interest in their illness; a better telling of their diagnosis; an early rather than late referral to a multidisciplinary team; continuity of care as well as participation in the management of their own illness. To help meet those needs strategic alliances need to be forged with academia, pharmaceutical and biotech industries, health and social care professionals as well as voluntary organisations.

Surgical procedures are not without hazards. How will patients be selected? Who will decide who has the operation? Will everyone be able to afford surgery? Or, does this become a procedure only for the wealthy? And, is it the best way to spend the money?

Regarding the development of new ideas – are we sharing all this globally, and if not, then why not? Is there equity in the access to treatment? We need to find solutions to far reaching issues such as cell growth - can it be controlled to prevent tumours? And how can we ensure the balance of levodopa in new cells? We also need to find a balance between procedural requirements for confidentiality and traceability

It is imperative to develop a dialogue between science and society. We need to effect change in attitude and how do we do this? By involving the patients' voice in the ethical and political debate. We also need to involve European social sciences and humanities as well as biomedical science. It is only by involvement, debate and partnership that we can effect behavioural change.