

# The primary care stroke gap

THE burden of stroke to individuals, families, and society is considerable. It is the leading cause of disability and the third most common cause of death in the United Kingdom (UK).<sup>1</sup> Disability has been described as 'the very stuff of general practice'.<sup>2</sup> It is therefore surprising that the role of the primary health care team in the management and support of stroke patients and their families has received negligible attention within the vastness of contemporary stroke literature. The main theme has been the involvement of general practitioners in stroke prevention; however, this is considerably less than the expressed and practical needs of disabled stroke patients.<sup>3-5</sup>

Stroke management in the UK is asymmetrical with the greatest effort expended during the early weeks, usually as a consequence of hospital admission, followed by negligible input during the succeeding months. Arguably, the process has become more asymmetrical as there is now reliable evidence that hospital-based stroke care using the model of a stroke rehabilitation unit confers improved patient outcomes.<sup>6</sup> There is therefore a simple (but erroneous) belief in equating stroke rehabilitation entirely with stroke unit care. A more helpful understanding is to consider the stroke unit as a proven platform on which to *begin* the recovery and adjustment process.

A case for the routine involvement of the primary health care team comes from community-based observational studies describing the longer-term consequences of stroke.<sup>7,8</sup> The emotional and social consequences of patients and their families may persist for several years after the onset of stroke.<sup>9,10</sup> The practical difficulties for patients with stroke include lack of information about their condition,<sup>4,11</sup> poor knowledge of the services and benefits available,<sup>8,12</sup> and fragmented community services.<sup>13</sup> A survey of patients six months after onset of stroke found that two-thirds had some residual disability, but less than half were receiving help of any kind.<sup>14</sup> Social activities may be restricted despite apparently good physical recovery.<sup>9,15</sup> Falls and associated morbidity are also common.<sup>16</sup>

Health care service structure is an important general condition for successful rehabilitation.<sup>17</sup> At present we know that the stroke unit is a structure which enables complex multi-disciplinary rehabilitation processes to be brought together and more effectively co-ordinated. However there is less certainty about the effectiveness of its individual process components. Community stroke rehabilitation research has progressed in the opposite manner. Several randomised control trials have examined specific intervention processes. Some of these have concerned the input of professions allied to medicine, such as occupational therapy<sup>18-20</sup> and physiotherapy,<sup>21</sup> while other trials have included very specific treatments, such as dressing<sup>22</sup> and mobility.<sup>23</sup> The trials have been small; however, the results are encouraging. Surprisingly, additional useful gains have been achieved with low levels of intervention — typically one or two visits each month. Unfortunately, these studies are not well known outside the stroke community and, as yet, have not influ-

enced service commissioners or primary care. A critical limiting factor, which contrasts with the stroke-unit, is the lack of a community-based health care structure to promote these positive findings. Uptake into routine practice has therefore been poor and, at present, involvement of the primary health care team in stroke is inconsistent. Sporadic examples of good practice are evident, but these stem from a few committed enthusiasts. No systematic approach has been developed for routine monitoring, problem identification, and co-ordination of services to assist stroke patients and their families as they continue to recover from their stroke and make life adjustments to its consequences. The lack of engagement of primary care in stroke is in particular contrast to other chronic diseases, such as asthma and diabetes where, in recent years, a primary health care model for their management has become so well developed that there has been a strategic shift in the location of care from secondary to the primary care setting. The challenge is to engage the primary health care team in post-stroke care to assess, support, and co-ordinate relevant services to minimise longer-term stroke morbidity. This is a difficult task, as primary care has become overburdened with work shifting from secondary care and by an increase in the 'consumerism' of patients. Yet opportunities exist, particularly in respect of practice nurses, nurse practitioners, and the newly extended role of community nurses. Also, the introduction of primary care groups/trusts responsible for the health care delivery for populations of approximately 100 000 means that each may be expected to have over 500 prevalent stroke cases — a sufficiently large group to warrant the development and implementation of a specific primary health care system.

What needs to be done? One recommendation has been for regular patient reassessments<sup>24</sup> to help overcome the commonly expressed feelings of isolation and abandonment. Recent patient-centred research has supported this recommendation;<sup>3,5</sup> however, the frequency and content of these contacts needs greater clarification. Three important community stroke challenges have been identified:<sup>25</sup> a longer-term perspective; addressing psychosocial and adjustment needs; and less emphasis on disability (restricted activities) and more on handicap (the consequences of restricted activities to an individual). A multi-disciplinary team approach is needed as the patient and carer problems are complex, diverse, and change over time.<sup>26</sup> Early discharge rehabilitation schemes are associated with equivalent outcomes to longer stays in hospital; however, such services have more to do with organisational survival (coping with hospital admissions) than a new paradigm of care for stroke patients. A larger vision, in which community stroke services become more comprehensively developed to offer routine and continuing contact, should be the aim. Community rehabilitation therapy teams with open referral systems are feasible<sup>27</sup> but do not appear to influence stroke-related psychosocial issues that become increasingly prevalent with time.<sup>26</sup> Interventions specifically addressing psychosocial problems remain poorly developed<sup>28</sup> but can

make a small contribution,<sup>29</sup> particularly for carers.<sup>30,31</sup> Both approaches are compromised unless they become fully integrated into primary care and this implies locality working rather than traditional secondary care outreach. The aim should be regular and routine contact of stroke patients and their families by the primary health care team, with a structured approach to continuing physical rehabilitation, co-ordinated access to supporting services, and psychosocial support. Clarification of the content, organisation, and delivery of the service are the pressing areas for research and will require careful development work and subsequent rigorous evaluation.

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# 'Valuing People' — a new strategy for learning disability for the 21<sup>st</sup> century: how may it impinge on primary care?

**L**EARNING disability is a developmental disorder characterised by 'a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood with a lasting effect on development.'<sup>1</sup> There are estimated to be approximately 210 000 people in England with severe and profound learning disabilities and the prevalence rate of those with mild to moderate learning disabilities is approximately 25/1000.<sup>1</sup>

Although in itself learning disability is not a clinical condition, it is associated with a two-and-a-half-fold increase in the prevalence of health problems (particularly neurological, behavioural and sensory), compared with a general practice control population, in those with moderate, severe, and profound learning disability.<sup>2</sup> Life expectancy is markedly reduced.<sup>3</sup> People with learning disability tend to experience a whole range of physical and mental health problems. A recent New Zealand study<sup>4</sup> of over 1000 people with learning disability found that 73% of those screened required

follow-up, principally with regard to vision, hearing, haematology, gynaecology, dental, weight, gastrointestinal, medication, and skin problems.<sup>4</sup>

One of the effects of normalisation in the United Kingdom has been to empty the large mental handicap hospitals; at the time of the last White Paper in 1971, 58 850 patients were in NHS hospitals or units, whereas there are now fewer than 10 000 in NHS facilities. There is evidence that former mental handicap hospital patients consult more frequently, and require more central nervous system drugs, than those with learning disability permanently residing in the community.<sup>5,6</sup> The policy of taking people out of institutions and placing them into community care may have meant that some adults with learning disabilities have disappeared into the community with little structured follow-up. There has been debate about who should provide their ongoing mental and physical health needs.<sup>7</sup> However, as a whole, those with moderate, severe, and profound learning disabilities are usually known to educational services and to the local authority. In some localities there are good special needs registers identifying this group; however, general practitioners (GPs) do not often access these registers.<sup>8</sup> There are now 53 400 people in residential care; 84 000 adults are receiving community-based services, including 49 600 in receipt of day services. It is believed that there are relatively more patients with learning disabilities in areas of social deprivation.

Thus it is generally accepted that there is a shortfall between what is being done and what could be done for patients with learning disabilities, in regard to their health.<sup>9-11</sup> The reasons for this are complex, but include access, advocacy, and communication difficulties. Someone with learning disabilities and cerebral palsy may rely on a wheelchair, taxi, and a carer to get to the doctor's surgery and voice his symptoms, which even for the most articulate of us may be difficult enough to convey. There may be further access and communication difficulties in patients from ethnic minorities whose first language is not English.

GPs need additional skills, resources, and training to help those patients who have learning disabilities; but principally, GPs need additional time, a commodity currently recognised as being in short supply. With notable exceptions, this 'Cinderella' subject has been ignored or given minimal teaching time in medical schools and in GP education.

The 'Valuing People' strategy focuses on those with learning disabilities first, rather than on professionals or institutions.<sup>12</sup> The strategy proposes that those still in long-stay hospitals will be in 'more appropriate accommodation' by April 2004, and that 'all people with learning disabilities will have access to a health facilitator by June 2003, be registered with a GP by June 2004, and have a 'Health Action Plan' in place by June 2005. Government expects health facilitators, in partnership with primary care nurses and GPs, to be responsible for offering and completing these health action plans, which will be part of the individual's 'person-centred plan'. 'The health action plan will include details of the need for health interventions, oral health and dental care, fitness and mobility, continence, vision, hearing, nutrition and emotional needs as well as details of medications taken, side-effects, and records of any screening tests.'<sup>11</sup> Facilitators may be community learning disability team

members, probably nurses.

Health action plans will be offered at 'transition,' with a process of ongoing referral, then at other social landmarks, such as leaving home to move into a residential care service, moving home from one provider to another, moving to an 'out of area' placement, etc.

The transition health action plan would be an excellent arrangement for all concerned. It is the time when people with learning disabilities are moving on from supervision by educational and paediatric services. A plan of proposed health review and interventions could be drawn up with appropriate timing for the individual. The 'social landmark' health action plans are a novel idea, and should prove very useful in informing new carers and other professionals. My view, however, is that patients' health needs would be better served by appropriate regular review and continuity of care where possible. In its present form the White Paper seems to fall short on how primary care is to be involved in the action part of the plan. Implementation here is all-important if the patient is actually to benefit from the process. It is likely that GPs' surgeries will be where much of the individual's health action plan will become reality. The action plan might include simple lifestyle targets, such as weight reduction or smoking cessation, aimed at the many adults with mild learning disability who tend not to have additional problems and are able to self-advocate. I assume that the identification and facilitation process is particularly targeting those who cannot take responsibility for their own health and who are most likely to have unaddressed health problems; those with severe and profound learning disability, and probably those with moderate learning disability or with specific conditions, such as Down's syndrome.

It is not clear how health action plans relate to health checks. Both need to address maintenance of health and improvement where possible, i.e. targets need to be set for each individual. The Royal College of General Practitioners recommended regular health checks in 1990 and confirmed this in the terms of reference of the Learning Disability Group in 1999.<sup>13</sup> The NHS Executive in consecutive publications<sup>14,15</sup> also stated that it was good practice to perform regular health checks at appropriate intervals. However, there is no mention of health checks as such in the White Paper. An unpublished audit of RCGP members' views last year showed that 74% thought structured health checks were 'a good idea ... as long as someone else does them'.

There is a set of 15 health targets developed through international collaboration, consultation, and literature review; these are for conditions which are highly prevalent, easily detected, and amenable to readily available treatments. There are major problems in obtaining evidence-based criteria in the field of developmental disability medicine; however, these particular targets are reasonable and under consideration by the World Health Organization.<sup>16</sup> Many are included in the recommendations of this White Paper; however, the identification and treatment of mental health problems, epilepsy, gastro-oesophageal disease, constipation, thyroid disease, and osteoporosis are not specified. Further, the ensuring of full vaccination status, and referral on to a genetic clinic for patients where there is no definitive aetiological diagnosis of the condition, are also not covered by

this White Paper. If patients are to get the care to which they are entitled, then GPs and in some cases consultant colleagues (although much might be delegated to nursing colleagues, both specialist and within primary care), will need to be involved in some health action plans.

So how is primary care to respond to the aspirations of this White Paper? 'Valuing People' identifies increased need and 'shortfalls in primary care provision' and proposes 'key actions ... to reduce health inequalities.'

Cinderella certainly needs to go to 'the ball' and it looks as though the transport will be facilitated. Those apparently tasked with arranging the ball have not yet been given much encouragement, and are preoccupied with other issues. The 'Valuing People' strategy has initiated a process. It now needs to do everything necessary to achieve its goal — for Cinderella's sake.

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