

## **YOUNG PHYSICALLY DISABLED ADULTS: OUT OF SIGHT, OUT OF MIND? – (1) INTERVENING TO IMPROVE LIFE IN A CARE HOME**

Over the past 20 years many papers and reports have been written on the needs of younger adults with a physical disability. In the 1970's and 80's those who required institutional care were accommodated in hospitals for the 'young chronic sick', although some who were 'difficult to place' languished for long periods in acute hospital wards. Many of the hospitals for the 'young chronic sick' were old, unattractive and isolated from 'the community'. These hospitals have now closed, and those who previously would have been admitted are now supported in Care Homes or in their homes.

People classified as 'young physically disabled' are by no means a homogeneous group. They include people who are severely disabled as a result of conditions such as multiple sclerosis, brain injury, stroke, epilepsy, Huntington's Disease, muscular dystrophy/spinal injury, cerebral palsy and the ataxias. Most of the conditions are neurological, and for some (eg brain injury and Huntington's Disease) the description 'physical disability' is not really appropriate. However from the point of view of service provision – whether for people living at home or in a care home- the label 'young physically disabled' persists.

### **The situation in Glasgow**

There are some 700 people aged 65 years and under who are permanently resident in a care home within NHS Greater Glasgow area: with at least 60 new admissions per annum. Over 100 of these are people with traumatic brain injury and probably another 300 at least with alcohol related brain injury. The remainder have a variety of other conditions such as multiple sclerosis, Huntington's Disease, brain tumour and stroke, together with a number who have varying degrees of learning disability. Our records identified 10 Care Homes with 10 or more adult residents under the age of 65 years. In addition there were 34 homes with fewer than 10 younger adult residents, several having only one or two.

There are of course many more younger adults with a severe 'physical' disability who live in their own homes and this number cannot even be estimated – not least because of the difficulty in defining 'severe' and 'physical' disability. However the number in the NHS Greater Glasgow population (about 900,000) certainly exceeds one thousand.

### **Our work in care homes**

A small 'intervention team' (comprising a clinical nurse specialist in palliative care, an experienced activities promoter/researcher and a consultant in public health medicine) made regular visits over a number of weeks to the three homes with the greatest number of young adult residents - in order to get to know the managers, staff and residents themselves. The team who had close links with the Nursing Homes Medical Practice – which in Glasgow provides general medical and additional services for the majority of Care Homes (nursing) and residents.

Two of the three Care Homes with the greatest number of younger adults provided a separate wing in a relatively new building in which most of the residents were elderly. The third care home provided facilities exclusively for up to 24 younger adults, although there was a larger

building for elderly people on the same site. The environment in which the younger people lived in each of the three homes was pleasant enough, but there was a general feeling of very little going on, and of residents spending most of the day in their rooms. A variety of interventions (mainly activities, but with some physical therapies) were introduced at each of the three homes, but it was decided to focus on efforts on the home which had the most dependent residents and the greatest need for therapeutic input.

When we first visited the care home the majority of residents spent most of their day in their rooms watching television. Some residents were seated in communal areas, but with nothing to do or occupy their minds. The most disabled residents lay curled up in bed, with obvious contractures. There was a young man with a facial swelling who appeared to be in pain and a woman on PEG feeding, the need for which clearly required re-assessment. There was general concern about oral health and skin care. Very few of the residents left the home on a regular basis to pursue activities outside. When materials were left to give residents something to do (eg blackboard and chalk, paper, games) there were found at a subsequent visit to have been 'put away' somewhere.

A number of circumstances led to the appointment of a new and enthusiastic nurse manager and two new care assistants in the home. Our 'intervention team' was able to engage with the nurse manager in a number of initiatives to improve the environment, change the culture (helping residents to achieve their full potential) and to establish a range of activities from which each resident could choose. The team itself provided training to improve oral and skin care, and to encourage staff to identify and help resolve problems. The need for a physiotherapist was obvious, but it was possible to secure a person with the appropriate skills for only one session per week. Referrals were made to a number of specialists – for example to nurse specialists in palliative care, multiple sclerosis and epilepsy; members of the Community Physical Disability Team; a dental practitioner and consultants in rehabilitation medicine. More recently an occupational therapist, a speech and language therapist, and a holistic therapist have been recruited to the team, working one or two sessions per week.

### **What has been achieved?**

Each member of the team has contributed their particular skills, knowledge and expertise to enhance the social and health care of each individual. The paper illustrates how much can be achieved by creative and enthusiastic front-line workers in a setting..

#### ***The home itself (by the nurse manager)***

Redecoration and more imaginative use of communal spaces, the availability of things to do and a general 'buzz' as staff go about their work and "talk to - rather than over" - residents is a complete change from the previously desolate interior of the Home. The nurse-manager, encouraged by the 'intervention team', has established an evolving programme of developments – including continuous assessment of the needs and wishes of the of each resident and creatively thinking how these could be met; developing personal learning plans for each staff member; providing a variety of opportunities for staff to learn in the work context; and showing all staff members respect and encouraging them to come forward with new ideas.

Possibilities for the future include involvement of nurses, students (eg social care, arts and creative activity, complementary therapies) and volunteers; and securing transport to enable residents to engage in a wider range of outside activities

### *By the physiotherapist*

Residents living in the care home have highly complex needs. Prior to the appointment of the physiotherapist and nurse manager and involvement from the NOF team, many patients spent their day in bed with only the television to occupy them. None of the residents received physiotherapy, and for the majority there was no record of physical disability assessment or plan of continuing care.

The physiotherapist highlighted the importance of initial and continuous assessment for each resident in order to identify the potential of each resident to improve wellbeing and gain more independence. Involving staff with the care plan has helped staff to continue some of the physiotherapy when the physiotherapist was not available. Staff were able to make sense of what was being asked of them because the physiotherapist communicated with them by discussing individual residents, writing a care plan and also by having short learning sessions around important topics such as correct positioning, passive movements and the use of splints.

Achievements gained through physiotherapy assessment of residents and involvement with residents and staff included:

- One resident had the potential to walk with the use of a Standaid and two helpers (prior to this intervention the resident was in bed most of the day). Staff were now able to help this resident with walking
- Three residents were able to stand upright with the use of the Standaid. This helped their position and residents gained an instant feeling of achievement
- Improved position for most residents also improved their communication and feeding skills, thus increasing independence
- Six residents were re assessed for wheelchair and static chairs
- One resident was in pain and required an x ray to exclude dislocation of her hip and re assessment of analgesics from GP
- Splints, sleep systems and passive and active exercises were identified by the physiotherapist as requirements for the majority of residents; however there was often difficulty obtaining equipment and assistance.
- One resident was referred to the psychological support/counselling service provided for MS residents by Revive Scotland. This service is available to MS residents on an outreach basis.
- Three residents were referred to the multidisciplinary team at the physical disability rehabilitation unit for further intervention.

- Referrals were made to the community physical disability team for speech, physio and occupational therapies.

### ***By input from specialists***

Referrals were made to:

*Physical Disabilities Unit:* to re assess some residents who were already known to the department and others who were “new referrals”

*Multiple Sclerosis Nurse Specialist:* to assess residents in the unit, provide advice and act as a link with the neurological consultant for advice.

*Palliative Care Nurse Specialist:* to identify some residents who required symptoms to be reviewed and she also had a direct link to the consultant palliative care specialists at the hospice. One resident was admitted to the hospice for one month to have complex pain symptoms managed.

### ***By the holistic therapist***

People with multiple pathologies may not be able to express themselves in a conventional way. Pain, anger, anxiety or agitation is sometimes expressed through body language or “challenging behaviour”. The involvement of a holistic therapist in the care home has been invaluable.

On almost all occasions when the holistic therapist has intervened, she has made a visible difference. Post treatment residents appear more relaxed. Others who often appear to be introverted became more talkative. Residents often become more responsive. One particular gentleman began to communicate, having never spoken to staff before!

### ***For staff***

Staff were helped with the following:

- Practical skills training at the workplace. The physiotherapist identified the above problems and shared this with the staff. Practical sessions with the staff enabled them to enhance their skills and to identify individual resident’s potential to improve their quality of life
- Communication skills were improved between the staff, GP and physiotherapist. Staff were made aware of various agencies they could contact for further help and advice for example
  - Physical Disability Team
  - MS Nurse Specialist
  - Revive MS Therapy Services
  - Huntington’s Disease Advisor
  - Palliative Care Nurse Specialist

- Providers of various equipment
- Care Home staff, including the most junior, benefited greatly from being encouraged to put forward ideas and suggestions for improving residents' wellbeing, and for increasing effectiveness and efficiency (including ideas for the elimination of wasteful practices). They were also encouraged to repeatedly question from the time of admission - "where could this resident move on to from here?"

### **Some lessons learnt**

The most distressing finding in this Care Home (that was not dissimilar to the situation in the two other Care Homes which we visited) was the neglect of the young residents: in terms of preventing deterioration of physical, mental and social function, and failing to address basic needs - such as mouth, dental and skin (including stoma) care. Compared with people living in their own homes there was a reluctance in the part of specialist nurses, allied health professionals and of consultants in rehabilitation medicine to accept referrals of these residents - although requests made to individual professionals on a personal basis were usually responded to.

A more encouraging discovery was how much can be achieved by a small team of enthusiasts from a variety of disciplines working together with care home staff . A complete turn-round of the home and of the practices of staff was achieved, despite all those involved (apart from the nurse manager) being available in the Home for only one or two 3-hour sessions per week. There is still need for considerably greater input from physical therapists and for equipment, but the model of multidisciplinary working has great benefits for residents and staff and is worthy of replication elsewhere.

A third critical issue is the importance of making all care home staff aware of all the sources of help and support which are (or should be ) available. The nurse-manager stressed "the importance of knowing the right people" and "who to contact and value" . Bringing specialists in not only greatly assists in the management and wellbeing of residents, but also provides a valuable learning opportunity for staff. Contact with such specialists brings a welcome influx of new knowledge, skills and attitudes, and helps to promote a true learning environment.

There is a need to quash the myth that care-workers do not need to know - even should not know – the underlying cause of a resident's disability. People with multiple sclerosis, Huntington's Disease, muscular dystrophies and brain injury for example sometimes exhibit characteristic but disturbing personality traits and physical signs (eg relating to gait). Care workers and other staff need to know about these characteristics so that they can be accepted as a consequence of the condition and the resident not made to feel uncomfortable or subjected to blame.

### **A better method**

One facility we have visited which is designed and staffed to meet the needs of younger adults with a severe physical disability is operated by the Red Cross in Irvine, Ayrshire (Options for Independence, Scotland). The cost per resident is some £250 per week more than the sum made available by local authorities for younger physically disabled

residents of regular care homes. However this is substantially less than the cost of providing supported accommodation or sheltered housing such as is provided for people with learning difficulties or mental health problems, and also substantially less than accommodation in a specialist facility for people with alcohol-related brain injury.

The atmosphere at 'Options for Independence' is entirely different from that experienced in the care homes that we have worked in. Autonomy, choice, a diverse range of opportunities, freedom to be yourself and support and encouragement to live to full potential are immediately evident. However for younger physically disabled adults in care homes elsewhere the norm appears to be assessing what people cannot do rather than what they can or could do, caring rather than enabling, being overprotective, and providing only minimal opportunity for leading a normal life.

## **Conclusions**

This interventive study has provided a possibly unique insight to the lives of many of our most vulnerable young adults. For care homes, the focus of attention is almost exclusively older people - because they are by far the majority. However many of the younger adults have perhaps 30 or 40 years more to live, compared with an average now of only a few months for older people. The total years to be 'looked forward to' is therefore considerably greater for the young people, and their needs are entirely different. Care homes for older people do not provide a satisfactory environment or ethos of care and support for younger adults. Younger adults need the help, encouragement and services/opportunities to enable them to live as nearly as possible to their potential in terms of physical, mental and social function. These requirements cannot be met from the resources allocated to the care of elderly residents.

It is unreasonable that the great majority of younger 'physically disabled' people in care homes should receive a far lower level of services and opportunities, and thereby enjoy a far less satisfactory quality of life, than people with disabilities which relate to mental health. Very few if any 'physically disabled' adults under the age of 65 years (and possibly older) should be accommodated in a care home with older people. And care homes with a specific facility for younger physically disabled people should be adequately resourced to provide the services and opportunities that are needed: or, alternatively and perhaps preferably, these resources should be provided for directly by the health service. However the best solution is almost certainly to provide and adequately resource purpose built facilities such as those provided by the Red Cross in Irvine, so that younger adults can receive rehabilitation other services and opportunities they need to live to their full potential - and where greater independence is possible- to transfer to sheltered housing and/or support accommodation outside.

## **Recommendations**

1. AHP Training Team staff to have a primarily clinical role and (as with other health professionals who provide clinical input to Care Home residents) to engage care home staff (and where appropriate family members) in the therapeutic process.
2. Community Physical Disability Team members to provide a service for people in care homes on same basis as for people living at home - but without requirement

- for two professionals to be involved before accepting a referral and with other change.
3. Physical Disability Rehabilitation Unit staff to provide advice and therapeutic input to care home residents.
  4. Campsie House (with capacity for 24 residents) to be further developed as a model care home for younger adults with a severe physical disability, by
    - a. increasing senior physiotherapy input from 3 to 9 hours per week
    - b. providing continuing input from a senior nurse whose main responsibility is for the wellbeing of younger adult residents in all care homes. Duties to include establishing and maintaining working relationships with 'external' NHS organisations and staff who could provide interventions and advice for care home residents; training; and fostering collaboration between the various professionals involved.
    - c. establishing posts for junior (possibly newly qualified) OTs and speech and language therapists, to work part-time with the senior physiotherapist and specialist nurse.
    - d. continuing to encourage nurses, social work and health care and complementary therapy students to work in the home as part of their training – to develop their interests and skills, and 'open up' the Home to activate influences.
    - e. providing much needed equipment
    - f. continuing to change the culture to one of continuously determining the potential for improvement so that every resident is able to live to full potential in terms of physical, mental and social wellbeing.
  5. Further research is required into the views of users and user groups regarding the issues that are important to them.

## *Annex*

### **How the lives of younger people living in the unit have improved**

#### ***By input from the physiotherapist***

“Soon the residents’ day changed from the usual lying on bed most of the time to staff interacting with residents for example to assist with walking.

“A number of residents within the home have Multiple Sclerosis (MS). Help with positioning is often required. The physiotherapist identified that some residents would benefit from the use of a StandAid”.

“Not only will this help the residents to stand and walk, this has helped us with moving and handling. The aid will also help us to initiate bladder and bowel training. We didn’t know such equipment existed, why did no one tell us about this before?” (Senior Nurse)

“we cannot believe Joe is walking it’s amazing, who would have thought Joe could walk?” (Care Home Staff).

“Joe I didn’t realise how tall you are, you’re doing really well, its lovely to see you walking” (Visitor to the home).

“The chair improved Dave’s position, he could hold his head up and this improved his eye contact. Soon, his communication skills improved, because his position was improved and he could see everyone!” (Holistic Therapist).

### ***By input from the holistic therapist***

People with multiple pathologies may not be able to express themselves in a conventional way. Pain, anger, anxiety or agitation is sometimes expressed through body language or “challenging behaviour”. The involvement of a holistic therapist in the care home has been invaluable.

“You can always tell when the holistic therapist has been visiting...not only do we get the benefit from the lovely aroma in the home...the residents she has worked with are more relaxed and content” (Care Assistant).

“Sometimes the resident is not able for physiotherapy, I always feel there is something to offer them when the holistic therapist is available” (Physiotherapist).

“Residents with challenging behaviour are less noisy, whilst others are more chatty” (Care Home Staff)

“Thank you. Jim isn’t shouting and he has managed to eat his lunch” (Care Home Staff).

“Rob was very talkative with me today he was discussing his family and the work he used to do” (Holistic Therapist). Prior to this the care home staff said they had not heard him talking!

“John enjoyed his walk today, he didn’t want to get out of bed before you gave him his treatment” (Physiotherapist).

### *Case Study: Joe*

Joe had an acquired brain injury, received as a result of an assault five years ago. He received few visitors and lay on his bed most days. He did not communicate and staff were not aware of his potential ability to improve. The deputy manager had a “hunch” that with physiotherapy input Joe may be able to make some improvement. The physiotherapist was able to assess Joe and she soon realised that he had potential to walk, talk and partially be able to feed and dress himself. A plan of care was implemented. A walking regime was initiated. Joe was walking with two staff supporting him. Staff were enthusiastic and worked alongside the physiotherapist. Soon Joe was using a StandAid.

The physiotherapist accessed a private company to measure Joe for a static chair. Care home staff often have difficulty accessing equipment for residents.

“Some people think that because the resident is in a care home we (the care home) should buy equipment, we have tried to obtain a chair for Joe from the usual NHS resources but nobody took responsibility, we were transferred from pillar to post. It’s ironic to think Joe would have received more if he had been living in his own home...but because he is in a care home he is punished further” (Care Home Nurse)

The chair improved Joe’s position and eye contact. Soon Joe’s communication skills was improved, albeit only monosyllabic answers to questions. However this has highlighted the fact that Joe can talk. His independence has been increased further, he can manage to part feed himself and he is able to help with dressing. His mental state also appears to have improved. Joe has been referred to the Physical Disability Team for a thorough assessment.