



To: Chief Executives, NHS Boards & Trusts
Medical Directors, NHS Trusts
Directors of Public Health
Directors of Social Work
Alzheimers Scotland
Scottish Huntington's Association
Headway Scotland
Scottish Head Injury Forum
PHIS
NHSQIS
NHS Health Scotland
Into Work
Momentum
Allied Health Professions
Voluntary Health Scotland

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REVIEW OF PROGRESS SINCE SNAP REPORT ON HUNTINGTON'S DISEASE, ACQUIRED BRAIN INJURY AND EARLY ONSET DEMENTIA.

I enclose a copy of the Executive Summary of the Review commissioned by Scottish Executive Health Department into services provided for patients with Huntington's Disease, Acquired Brain Injury and Early onset Dementia since the SNAP (Scottish Needs Assessment Programme) Report in 2000. The numbers of these patients are increasing and many have very complex physical, mental, social and vocational needs for many years.

The summary outlines key areas to be addressed in promoting best practice and continued improvement in the care of these patients. It emphasises the need for more information and planning to meet the health needs of these patients and their carers; greater involvement of patients and carers in planning and decisions about their care; and the need for closer working with the voluntary sector to ensure long-term rehabilitation, education, training and supportive care where it is required.

I am confident that attention to these measures will help to provide improved quality of life for these patients and their carers.

Please would Medical Directors in NHS Trusts forward to:

- relevant clinicians in neurology, neurosurgery, A&E, genetics, psychiatry, psychology, rehabilitation medicine and brain injury services;
- relevant clinical and community teams in rehabilitation and mental health and brain injury services;
- all general practitioners;
- all Directors of Nursing for relevant nurses and health visitors;
- relevant advisory committees particularly in neurosurgery, neuropsychology, genetics, psychiatry, clinical psychology and rehabilitation;
- advocacy services for these groups.

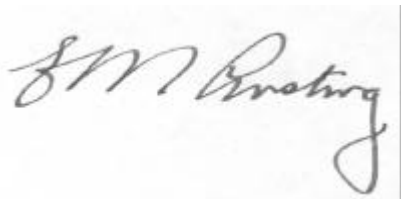
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Please would Directors of Public Health forward to:

- CPHMs and Public Health Specialists with responsibility in these areas.

Please would Directors of Social Work forward to relevant teams for these client groups.

Yours sincerely

A handwritten signature in black ink, appearing to read 'E M Armstrong', written on a light-colored background. The signature is cursive and somewhat stylized.

DR E M ARMSTRONG

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REVIEW OF PROGRESS SINCE SNAP REPORT ON HUNTINGTON'S DISEASE, ACQUIRED BRAIN INJURY AND EARLY ONSET DEMENTIA

EXECUTIVE SUMMARY AND RECOMMENDATIONS:

On the positive front:

1. There is plenty of evidence of good services in several important areas of planning and care in Ayrshire, Fife, Glasgow, Grampian, Tayside/Angus.
2. Planning is going ahead in Highland and other areas.
3. The main thrust of the forthcoming White Paper on Health, and the Social Justice Framework, serves to support the needs and care of people with problems such as these. Policy on joint futures, single shared assessment, user focus and public involvement, supporting disability rights, and managed networks lend support for action in favour of groups such as this.
4. Regional workforce development units will also help to address staffing issues.
5. There is commendable commitment amongst individuals, groups and some planners to better strategies, better plans, better services which are better tailored to people's needs, and a better quality of life for users and carers.
6. The SNAP Report has probably had a beneficial effect on the pace of progress, and this includes greater demand on existing services.
7. The Scottish Executive Strategic Review into voluntary sector funding will also address issues raised in this review.

Room for improvement and recommendations

1. People with Huntington's Disease, acquired brain injury and early onset dementia, and their carers would benefit from the following at a strategic level :-
 - i. Opinion formers and decision makers to be more aware, willing to lead and co-ordinate endeavours to address the needs of these people.
 - ii. Where developments are patchy and in need of improvement, there should be more awareness, strategic information and joint planning at a high level across sectors and involving voluntary organisation.
 - iii. Where there are good ideas and developments, these should be made well known, described and applied across the country. This is particularly important for challenging areas, settings and groups of people.
 - iv. The voluntary sector should have greater influence on planning and services to support people with Huntington's Disease and early onset dementia. Firm leadership is necessary to develop services to support people with acquired brain injury, especially in areas such as long-term rehabilitation, care, education and training.

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- v. People in positions of responsibility should address specific shortages across the system – skills, resources, service co-ordination, planning, appropriate care packages, delays in access to care, care management to reflect changing needs, the challenges of rural areas. All these matters need energy, commitment and further work.
 - vi. We still do not know how many people are in need of services. Each area of the country should try harder and use all interested stakeholders, to meet the needs of their population in this regard
2. More education and awareness raising of staff, patients and carers about the hidden disabilities that these people experience is needed, with a view to increasing understanding and reducing social exclusion.
 3. Pilot Managed Clinical Networks – perhaps in Tayside, Glasgow and Fife – to promote managed pathways of care.
 4. Encourage statutory services to devise ways of funding the voluntary sector which are less short-term and fragmented, and more integrated into health and social work, particularly after a pilot has demonstrated a need for the service. The strategic review will help here.
 5. Encourage statutory services to use the needs assessment work carried out by the voluntary sector, which clearly show unmet need. SHA information is particularly useful where there is a service. Alzheimer Scotland should consider collecting more information on younger patients in order to identify needs.
 6. SEHD should commission a needs assessment of tertiary services in Scotland for ABI, including a review of the services provided by Astley Ainslie Hospital and Robert Fergusson Unit in the light of increasing numbers of patients surviving brain injury with severe impairment.
 7. Increase provision of vocational training schemes for people with these conditions who might benefit.
 8. Improve workforce planning to meet service needs. This will be helped by Workforce Planning Units.
 9. Pilot improvements in information on people with multiple needs, using Joint Futures and single shared assessment as a driver for this.

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