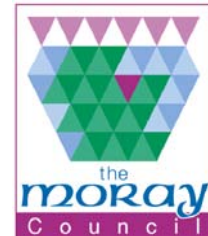


**Joint Future**



**Aberdeenshire**  
COUNCIL



# ***THE GRAMPIAN BRAIN INJURY STRATEGY.***

**2004-2010**

# **Contents.**

<b>1.</b>	<b>Foreword : Our Vision</b>	<b><i>p.3</i></b>
<b>2.</b>	<b>Executive Summary</b>	<b><i>p.4</i></b>
<b>3.</b>	<b>Some background.</b>	<b><i>p.5</i></b>
<b>4.</b>	<b>Definitions and numbers.</b>	<b><i>p.6</i></b>
<b>5.</b>	<b>Involving users and carers.</b>	<b><i>p.7</i></b>
<b>6.</b>	<b>What needs to change?</b>	<b><i>p.8</i></b>
<b>7.</b>	<b>What services are provided?</b>	<b><i>p.9</i></b>
<b>8.</b>	<b>What actions are planned?</b>	<b><i>p.11</i></b>
	<b>Appendices.</b>	<b><i>p.13</i></b>

# 1. Foreword: Our Vision.

- **The aim** of the Joint Grampian Strategy for Brain Injury is to take forward our commitment to improve the lives of people in Grampian who have a brain injury, and their families.
- **Their experiences** have informed our whole approach to this strategy, and will continue to be the key driver for change.
- **We have found** in Grampian, among all stakeholders, an appetite for change, an impatience with the status quo, and a willingness to strive for ongoing service improvement.
- There have been **significant advances** in service-user and carer involvement, and in joint working, in recent years and it is our hope that we can all work together to ensure even more progress during the lifetime of this new strategy.
- **In particular**, we should all strive to ensure that people with brain injury in Grampian have the opportunity to enjoy life in the most independent, active, and meaningful way possible.

***Grampian Brain Injury Strategy Group.***

## 2. Executive Summary.

- The sole **purpose of this Strategy** is to improve the lives of people with a brain injury in Grampian.
- The single **most effective way** to do this, is to invest in a dedicated Brain Injury Team to work across Grampian.
- Such a **Brain Injury Team** would be able to provide specialist support to people with a brain injury.
- In addition, they would be able to **provide training** for both carers and paid workers who provide support to people with a brain injury.
- It is acknowledged that **funding** for all the elements of such a team is not immediately available.
- **Other plans** are therefore described within this document which would be able to improve support in the short term.
- These **include** a lottery application submitted by Momentum, and the possibility of a new community-based rehabilitation service.
- It is felt, however, that the most immediate benefits could be achieved by all the agencies involved in developing this Strategy working together much more closely as a **Grampian Brain Injury Network**.
- This process **has already begun** as a by-product of this Strategy.
- It will be **further progressed** by a planned Grampian Brain Injury Seminar in March 2005, and by ongoing wide discussion with agencies across the North of Scotland.

### 3. **Some background.**

- **Significant shortcomings** in services for people with a brain injury have been widely recognised over the past two decades.
- **In particular**, there has never been a dedicated Brain Injury Team, and those few services that have existed have not been well co-ordinated.
- **Joint Future**, however, which involves health and social care staff working together more closely than ever before, is a new opportunity for improving services for everyone who needs them, including people with brain injury,.
- The **Joint Future Brain Injury Group** in Aberdeen, as part of joint community care planning in relation to brain injury, has, for several years, been identifying the extent of need, looking at current provision, highlighting service gaps, and recommending service developments.
- This has involved significant **investigation and consultation**, including literature searches, contacts with other areas of Scotland, a survey of relevant local agencies and organisations, consultation with carers and service-users, and also a Brain Injury Workshop.
- In the light of their **findings**, it became evident that Aberdeen City could not be focused on in isolation, and that future service provision needed to be considered in the context of a Grampian-wide strategy.
- As a consequence, the **Grampian Brain Injury Strategy Group** was formed, at the request of the Grampian-wide Partnership for Health and Social Care, as a short-life working group.
- **The aim** of the group was to examine all the issues in the wider context, and it involved Aberdeen City, Aberdeenshire and Moray Councils, NHS Grampian, the voluntary sector, and users and carers.

## 4. Definitions and Numbers.

- Brain injury is **defined** as damage to the brain acquired at some point after birth, but not due to any degenerative disease. It includes damage caused by traumatic injury, lack of oxygen, or infection but, for the purposes of this document, does not include stroke.
- The **consequences** of brain injury are wide ranging and include -
  - physical difficulties such as mobility and co-ordination problems.
  - cognitive difficulties including problems with memory, organising and planning, decision making, and insight.
  - emotional problems including anxiety, depression, and post traumatic stress.
- behavioural problems including inappropriate social behaviour, aggression, and inappropriate sexual behaviour.
- Brain injury has **significant implications** for families and carers, as well as for those with a brain injury themselves, but it is often only after a period of time that these become apparent, particularly in mild or moderate cases.
- **NHS Grampian statistics** classify brain injury as head injury. It should be noted, however, that people who sustain a head injury do not necessarily suffer brain injury.

### *What this means for Grampian.*

- There are no precise **statistics** on the incidence and prevalence of people with brain injury in the NHS Grampian area. McMillan <sup>(1)</sup> suggested -
  - 150 people per 100,000 will be moderately or severely disabled as a result of brain injury.
  - 350 people per 100,000 each year would benefit from rehabilitation following brain injury.
- Grampian's **population** is 531,200, suggesting annual figures of approximately -
  - 796 severely/moderately disabled.
  - 1858 likely to be in need of rehabilitation.
- In 2003 a total of 814 people were admitted to hospitals in Grampian, including, Aberdeen Royal Infirmary with head/brain injury. The **level** of brain injury was classified as follows -
  - 80% mild (up to 2 nights in ARI) = 670 people.
  - 10% moderate (up to 7 nights in ARI) = 81 people.
  - 11% severe (over 7 nights in ARI) = 91 people.
- **Of these** 423 (50.2%) were from Aberdeen City, 217 (25.8%) from Aberdeenshire and 117 (13.9%) from Moray. The remaining 85 were from elsewhere in Scotland.
- McMillan sets out a **framework** which can be used to decide the level of services required at each stage.

<sup>(1)</sup> *A Strategy for the Neurorehabilitation Centre and Care of Young Adults with Acquired Brain Injury in Greater Glasgow – T.M. McMillan, October 2003*

## 5. **Involving service-users and carers.**

- NHS Grampian, Aberdeen City, Aberdeenshire, and Moray Councils are **committed** to increasing the meaningful involvement of service-users in all aspects of the planning, design, review, and delivery of services designed to support people with a brain injury in Grampian.
- The **views** of service-users and carers have been gathered through discussions with members of the Brain Injury Grampian Group [*the BIG-Group*], which is made up of people who have sustained a brain injury and also of their carers.
- **Consultation** has also taken place with service-users who attend the Momentum Pathways Brain Injury Vocational Services.

## 6. What needs to change?

- Information from a major national report <sup>(2)</sup> indicated the following **gaps in services** -
  - lack of access to early expert multi-disciplinary diagnostic assessment.
  - poor co-ordination of clinical and social care.
  - mental health needs often not recognised or met.
  - failure to ensure access to skilled, sustained rehabilitation.
  - inappropriate long-term placement, and poor access to respite care.
- The report makes a number of **recommendations**, including -
  - greater involvement of users and carers in the integration of services.
  - agreed care pathways for professional and carers.
  - agreed standards of care to complement the care pathways.
  - improved access to information for professionals and service-users.
  - development and support of advocacy services.
- local audits of current impact on mental health service patterns.
- better co-ordination of current injury prevention programmes.
- improved collection of data to inform the planning of services.
- The report also emphasises that care should be **focused on the family** rather than on the injured person alone.
- Work in Greater Glasgow <sup>(1)</sup> identified a number of **shortcomings in service provision** for people with acquired brain injury. These include -
  - the narrow focus of medical restoration approaches.
  - high risk groups e.g. infants, adolescents and older people, being under-represented.
  - the need for rehabilitation over a lifetime.
  - difficulties in accessing rehabilitation.
  - little involvement of the brain injured person and their families in decision making.

<sup>(1)</sup> *A Strategy for the Neurorehabilitation Centre and Care of Young Adults with Acquired Brain Injury in Greater Glasgow – T.M. McMillan, October 2003*

<sup>(2)</sup> *Scottish Needs Assessment Programme: Huntingtons Disease, Acquired Brain Injury and Early Onset Dementia, 2000*

## 7. What services are provided?

### Services Specialising in Brain Injury.

- Those listed below are the only specialist services for people with brain injury.
- **Momentum** Brain Injury Vocational Centre offers vocational assessment, training, and development programmes for people with brain injury.
- The **BIG-Group** (*Brain Injury Grampian Group*) has been formed as a support group for the carers of people with brain injury.

### Local Service Provision.

- **Note:** The services below are general services which **may** see people with brain injury. Some, however, are not always appropriate given the geography of Grampian.

#### NHS Grampian.

- The Neurosurgery and Neurology Ward, **Aberdeen Royal Infirmary**, offers acute care and clinical assessment by a multi-disciplinary team, including neuropsychology.
- **Maidencraig** Rehabilitation Unit, Woodend Hospital, offers specialist rehabilitation for a number of conditions, including traumatic brain injury.
- The **Department of Medicine for the Elderly**, at Woodend, offers in-patient and day-hospital type rehabilitation to older people with a wide range of conditions, including brain injury.
- **Royal Cornhill Hospital** offers long term care for individuals with mental health problems, including those who have a brain injury.
- Ward 4, **Dr Gray's**, is used as a base to assess some individuals with brain injury.
- **GPs** may identify post-acute patients who have ongoing problems as a result of brain injury, and facilitate referral.
- **Horizons** Rehabilitation Centre, in Aberdeen, offers rehabilitation programmes tailored to meet individual needs.

#### Local Authorities.

- **Social Work/ Care Management** services are offered, to develop packages of care in co-operation with Primary Health Care, including Occupational Therapy.
- The **Moray Resource Centre** offers information, advice and support.

## Voluntary and Private Sector.

- The **Quarriers** Epilepsy Fieldwork Service provides support, information, and a liaison service, for those who develop epilepsy as a result of brain injury. This service is also available for families, cares and professional staff.
- **Margaret Blackwood** Housing Association offers supported accommodation, sheltered housing, and respite care.
- Some **Care Homes** can also provide long-term care for people who have sustained a brain injury.

## Outwith Grampian.

- National **specialist services** are offered by the Astley Ainsley Hospital, Edinburgh ; the Robert Ferguson Unit, Royal Edinburgh Hospital; and Scotcare, Lanarkshire.

## 8. What actions are planned?

- This Strategy takes account of the fact that **it will take time** and resources to realise all we would like to achieve.
- While it is essential to seek additional resources, it should also be recognised that **progress on some issues** can be made within the resources currently available.

### 1. Developing a Grampian Brain Injury Team.

- The Grampian Brain Injury Group Strategy takes the view that the report demonstrates the extent of **the need**, much of it unmet, that arises in Grampian, year on year, as a result of brain injury.
- The Group therefore proposes, as the **best way** of addressing this need, the development of a Grampian Brain Injury Team.
- **Aims** of a Grampian Brain Injury Team -
  - goal targeted treatment and rehabilitation, aimed at reducing disability and maximising independence in both community and hospital settings.
  - access for users and carers to information, support, and advice from hospital admission to discharge, **and** following on thereafter.
  - the facilitation of links with, and between, services supporting or providing a service to people with brain injury.

- The establishment of this Team is acknowledged to be a **long-term** target, given the lack of funding available to NHS Grampian and Councils at present.
- **Initially**, however, the workload/priorities of some existing staff being redefined to focus more on brain injury. Such staff, once identified could be encouraged and supported to begin to work as a Network of Brain Injury specialists. This will be considered by stakeholders as part of this Strategy's implementation process.
- At the same time funding could be sought, on a partnership basis, to establish a full-time community-based **outreach support worker**, who would work across Grampian with existing staff, as the first new member of the Team.

### 2. Lottery application.

- A Lottery application has recently been submitted by the BIG-Group and Momentum. If successful, the Project will provide **two community-based workers** across Grampian to support carers, enable users to regain confidence and progress personal development, and raise awareness of brain injury more widely.

### 3. Brain Injury Seminar.

- The Grampian-wide Partnership for Health and Social Care convene two seminars per year on issues of common interest and concern. It is planned that its first seminar in **March 2005** will be on brain injury. This event will allow the aims of this Strategy to be more widely known, and better progressed.

#### **4. Discrimination.**

- We need to tackle the issue of people with a brain injury being undervalued, stigmatised, or discriminated against, by the community in general, or by health and social care staff.

#### **5. Information.**

- We need to ensure that people with a brain injury have adequate and relevant information in an understandable format, that they are always present at formal discussions concerning themselves, and that they have whatever assistance or support they need.

#### **6. Access.**

- We need to ensure that people with a brain injury have increased access to the same social, educational, and employment opportunities as everyone else.

#### **7. Health provision.**

- We need to make sure people with a brain injury can access the same range of health provision that is enjoyed by the community in general.

#### **8. Recognition.**

- We need to ensure that the potential contribution of carers within service planning and provision is recognised and valued.

#### **9. Partnership.**

- We need to work more closely together with our partners across Grampian, and in the North of Scotland, for the benefit of people with a brain injury.
- The Leonard Cheshire organisation is keen to work in the area of brain injury in Grampian, and has approached various stakeholders directly on this basis.

# **Appendix 1.**

## **Grampian Brain Injury Group Membership.**

Mr Sandy Reid, NHS Grampian. (Chair)

Mrs Lynn Boyd, NHS Grampian.

Mr D Boynton, Aberdeenshire Council.

Mr Alisdair Chisholm, NHS Grampian.

Mrs Sally Chisholm, Moray Council.

Rev James Falconer, NHS Grampian.

Dr Helen Gooday, NHS Grampian.

Mrs Lesley Graham, Moray Council.

Mr Derek Grant, Discharge Planning Team.

Mr Larry Gray, Convenor, Brain Injury Grampian Group.

Mr Ray Inkster, Aberdeen City Council.

Mrs Rose McKechnie, NHS Grampian.

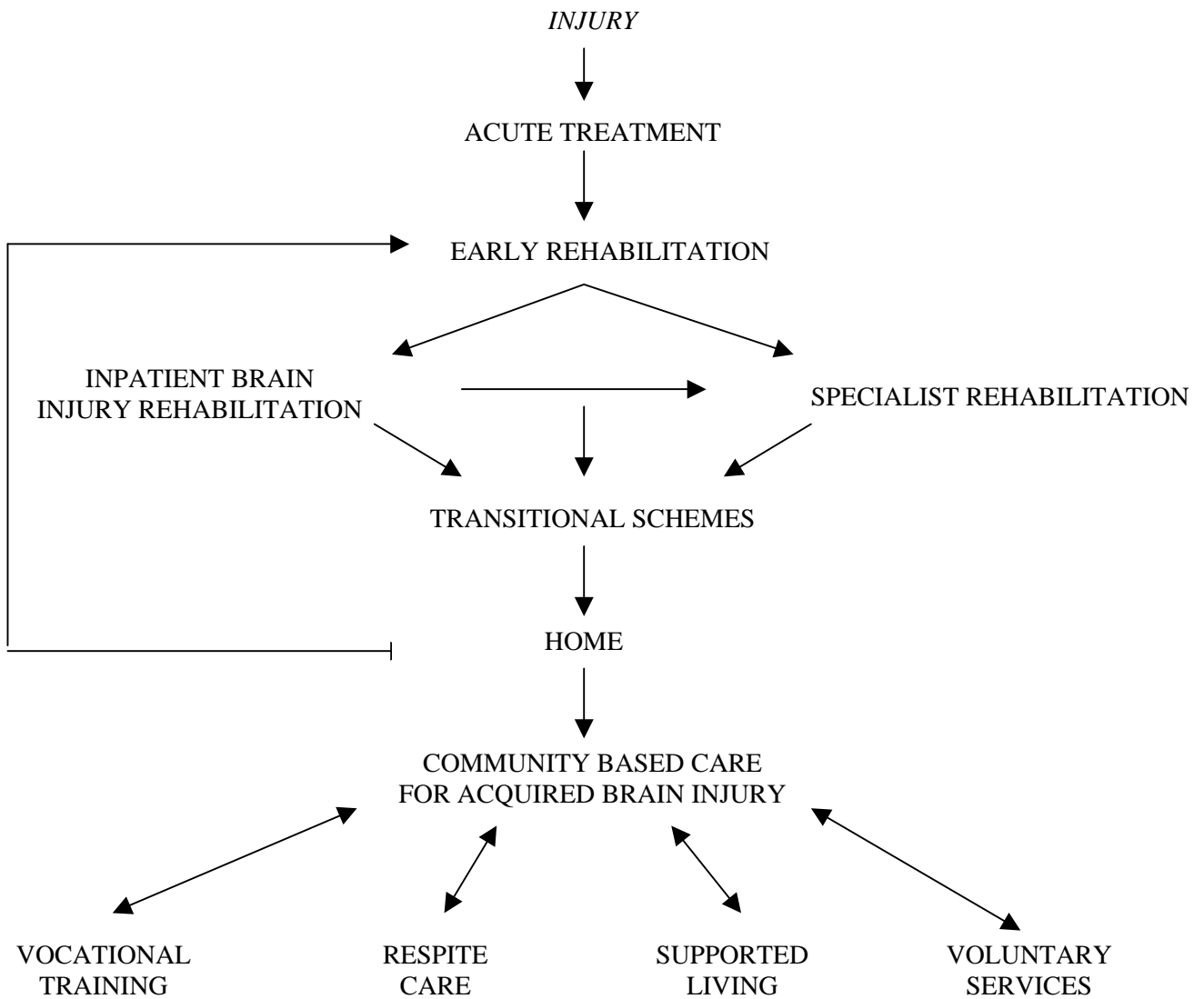
Ms Elinor Smith, NHS Grampian.

Mrs Dorothy Strachan, Momentum.

Dr Fiona Summers, Chair, Aberdeen Joint Future Brain Injury Group.

Ms Sally Wilkins, Aberdeenshire Council.

## Appendix 2.



A model for neuro-rehabilitation services from McMillan and Oddy (2001)