

REGISTERED  
NURSING HOMES  
AND PEOPLE WITH A  
TERMINAL ILLNESS

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A GUIDE TO  
GOOD PRACTICE

*Report of a Working Group of  
the Scottish Partnership Agency  
for Palliative and Cancer Care*



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November 1994*

# Scottish Partnership Agency for Palliative and Cancer Care

The Scottish Partnership Agency for Palliative and Cancer Care brings together voluntary and statutory bodies concerned with palliative and cancer care to promote the enhancement and development of services for patients and families throughout Scotland. Its objects are:

- *To establish and maintain effective links for communication among all those bodies involved with the provision of palliative and cancer care services in Scotland;*
- *To facilitate the participation of voluntary sector groups and organisations in developing palliative and cancer care services in Scotland;*
- *To facilitate planning, co-ordination, and consultation between the Partnership Agency's constituent members and the central departments of Government and related bodies; and*
- *To encourage education and research to improve the quality of palliative and cancer care.*

*For further information contact*

**Scottish Partnership Agency for Palliative and Cancer Care**

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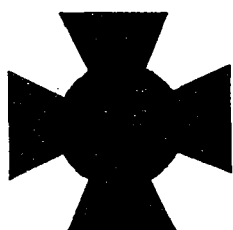
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# Foreword

This Guide to Good Practice has been produced by a Working Group set up by the Scottish Partnership Agency for Palliative and Cancer Care and comprising specialists in the care of terminally ill people, representatives of health boards and of the registered nursing homes (*Annex 1*). It is offered:

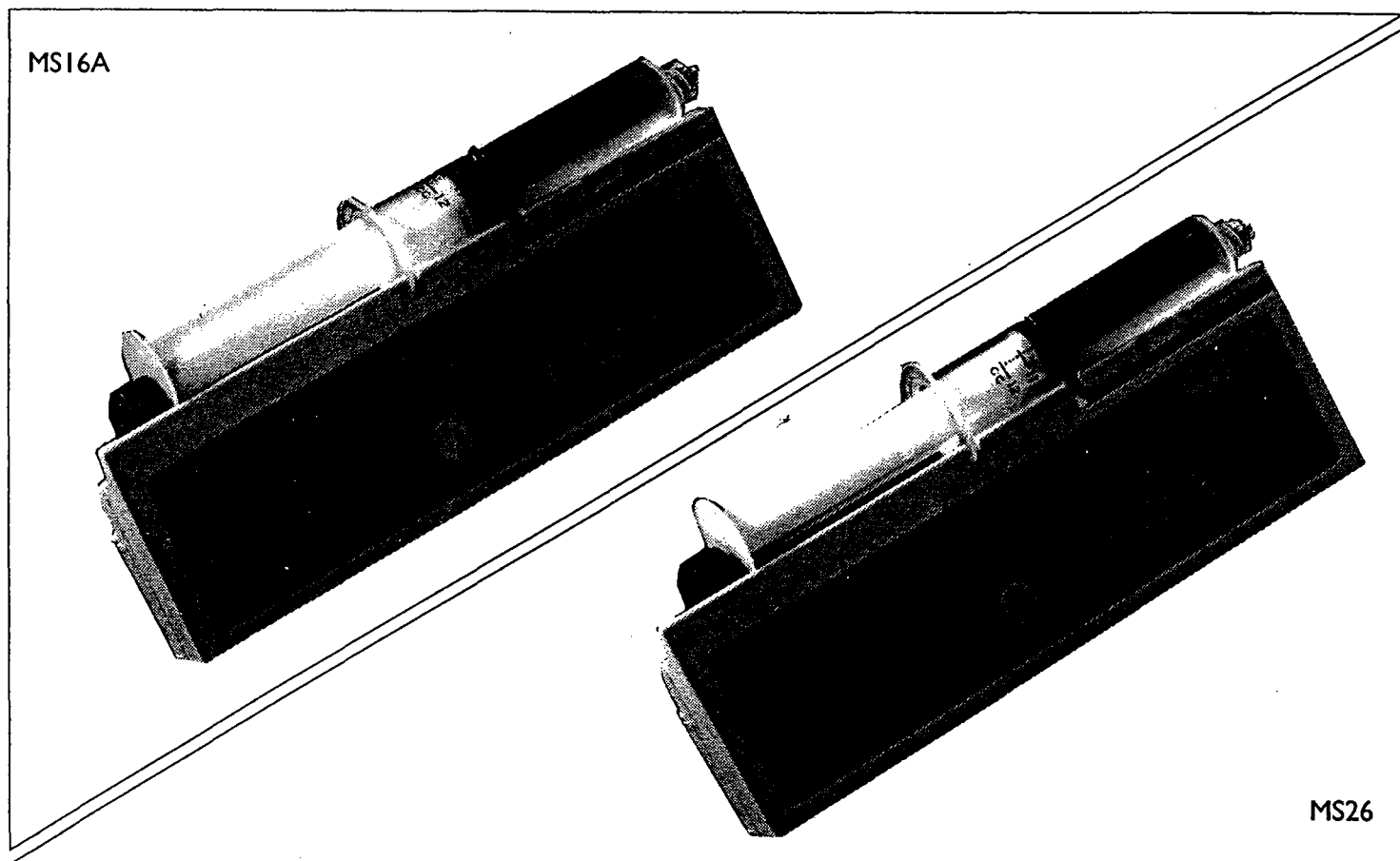
- 1 to health boards as an aid for those responsible for the registration and inspection of nursing homes;
- 2 to nursing homes as a guide to good practice, for those seeking or already holding registration for care of people with a terminal illness;
- 3 to the Scottish Office Home and Health Department as the basis from which to develop further guidance about the standards which should be required of nursing homes seeking to care for those with a terminal illness.

The Scottish Partnership Agency for Palliative and Cancer Care believes that private nursing homes have an important place in the spectrum of care for people with a terminal illness, complementing the specialist palliative care provided by hospices and specialist NHS units and teams and drawing on their specialised knowledge and expertise.

The ultimate objectives must be to provide a range of services capable of coping with and adapting to individual needs whether in the individual's own home, nursing home, hospital, specialist unit or hospice and having in place the means to transfer and share skill and knowledge across these facilities for the betterment of patient care. Health Service units, hospices, nursing homes and community based staff need to work together in a spirit of co-operation in order that all patients and their families can have access to a comprehensive, high quality palliative care service.

D T WRIGHT  
*Working Group Chairman*

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# Introduction

Registration of nursing homes in Scotland is governed by the *Nursing Homes Registration (Scotland) Act 1938* and the subsequent amending regulations. Inspection and registration is carried out at present by local Health Boards. This responsibility is currently under review but whatever the outcome of that review there is a need for clarity about the standards to be expected of a nursing home providing care for people with a terminal illness.

Each Health Board currently devises its own criteria for registration for care of the terminally ill without any central guidance. *Model Guidelines for the Registration and Inspection of Nursing Homes for the Elderly*<sup>(1)</sup> were produced in 1989 and similar guidelines for Independent Hospitals and Nursing Homes providing Acute Services came out in 1992.<sup>(2)</sup> Guidelines relating to people with learning disabilities and for people with dementia were published in 1994. No such guidance has been available on nursing home care for people with a terminal illness, with the result that proportions of registrations vary widely across Scotland. The registration criteria, standard of care and quality of service demanded by individual Health Boards varies considerably due to the lack of a more standardised national approach.

Demographic trends and Government policy in relation to private health care have resulted in a substantial increase in registered nursing home provision in Scotland. (*Annex 2*). The Management Executive of the NHS in Scotland together with Health Board General Managers agreed in 1991 that some guidance was desirable for Health Boards, as registering authorities, on standards of care for people with terminal illness in registered nursing homes. The Joint Working Group on Health Care of the NHS in Scotland suggested that a national statement of good practice might be produced in order to facilitate broadly similar standards for registration of nursing homes for the care of people with terminal illness across Scotland. The Scottish Partnership Agency for Palliative and Cancer Care was asked to assist in drawing up the guidance.

In 1994 a project was set up by the Scottish Office Home & Health Department to establish national standards for registration and inspection of registered nursing homes (the collaborative Standard Setting Project). The Scottish Partnership Agency hopes that the Project may find this guide to good practice helpful as a basis for the development of standards for the registration and inspection of nursing homes caring for people with a terminal illness.

## Care of the Dying

All nursing homes today properly regard it as their responsibility to care for patients who are dying from the multipathology of old age until their death. The principles of good practice identified in the Scottish Health Service Advisory Council (SHSAC) report *The Care of the Dying and the Bereaved in Scotland* <sup>(3)</sup> will be relevant and helpful to managers in this respect. The report was published in 1991 by a Working Group of the SHSAC. Its remit was

*“to highlight recent developments for the care of the dying and the bereaved; to identify existing areas of good practice; and to make recommendations on the methods whereby the philosophy and practice may be realised in different care settings”.*

The Report recommended that each Health Board should develop a strategy for the enhancement of good practice in the care of the dying in all settings and many of its recommendations and principles will be directly applicable and relevant to care of the dying in registered nursing homes.

All people who are dying should have a right to the best possible care for themselves and support for their family and to have their dignity, privacy and rights to choice respected. Those dying of a **terminal illness** may however have additional needs which may require **specialist palliative care**.

# Terminal Illness

The following definition is suggested:

*The patient who has a terminal illness is one who is suffering from an active and progressive disease, whose death is certain in the not too distant future, and for whom treatment has changed from the curative to the palliative.*

The definition should not be assumed to apply only to cancer

*“... heart disease, strokes and respiratory disease are also major causes of expected deaths, often with strong physical symptoms. While the pain and physical deterioration caused by these conditions may be less intense than that caused by cancer, their duration may be much longer. People suffering the acute phases of such illnesses will require pain control and at times of remission the possibly slower rate of deterioration may mean that they will also require more intensive social support”.* (NAHAT report “Care of People with Terminal Illness 1991<sup>(4)</sup>)

In Scotland in 1992, 32% of all deaths were due to heart disease, 25% to cancer and 8.5% to strokes. (Source: General Register Office for Scotland)

# Palliative Care

*“Palliative Care is the active total care of patients whose disease is not responsive to curative treatment.*

*Palliative Care:*

- *affirms life and regards dying as a normal process;*
- *neither hastens nor postpones death;*
- *provides relief from pain and other distressing symptoms;*
- *integrates the psychological and spiritual aspects of patient care;*
- *offers a support system to help patients live as actively as possible until death;*
- *offers a support system to help the family cope during the patient's illness and in their own bereavement.”* (Report of a WHO Expert Committee on Cancer pain relief and palliative care (1990) <sup>(5)</sup>)

Palliative medicine is the medical practice of palliative care and is now recognised as a speciality by the Royal Colleges. While specialist palliative care has come to be identified with the hospice movement it is also available in NHS continuing care units and elements of it are increasingly available alongside treatment in acute wards and cancer centres. Whereas elements of palliative care can be offered in a variety of settings, including nursing homes, specialist palliative care requires a multi-disciplinary team of professionally qualified staff specialising in palliative care.

*Palliative Cancer Care Guidelines* <sup>(6)</sup> were published in 1994 by the Scottish Partnership Agency and the Clinical Resource and Audit Group of the Scottish Office Home and Health Department. The Guidelines are mainly concerned with the needs of people with cancer although the principles apply to any progressive incurable disease. The Guidelines set out the “Factors which underpin the provision of palliative care” and “Factors facilitating good practice in palliative care” from diagnosis to the terminal stage and bereavement. Nursing homes aiming to provide a high quality of care for patients with progressive terminal illness will find the Guidelines helpful.

## Hospices

Hospices specialise in palliative care. They differ from private nursing homes in employing their own multi-disciplinary team of palliative care specialists, resulting in high costs which private nursing homes may find prohibitive. A Hospice is registered as a charity and makes no charge to patients or relatives.

There are now fourteen voluntary hospices in Scotland providing a range of in-patient care, day care and home care. They are representative of a movement which has shown the way, in Britain and further afield, to providing excellence in palliative care:

*“The hospice is, ideally, not only a residential centre but a resource centre from which skills, support, training and information on palliative care reach out to complement the skills of those providing primary and community care and to embrace the needs of the terminally ill person and his or her family circle”* (NAHAT report 1991) <sup>(4)</sup>.

The small number of hospices and specialist NHS units in Scotland do not have the capacity however to meet the needs of everyone dying from a terminal illness. The increase in the elderly population over the next few years will make this even less possible. (*Annex 3*). Registered nursing homes are likely therefore to find themselves caring for more terminally ill patients in need of some elements of palliative care.

## **Provision of Terminal Care in Nursing Homes: *Recommendations for Good Practice***

This guidance relates only to the standards and resources which registered nursing homes seeking to care for people with terminal illness should provide in addition to those already required for their registration.

The *Model Guidelines for the Registration and Inspection of Nursing Homes for the Elderly*<sup>(1)</sup> cover requirements general to all nursing homes for the elderly and this Guide to *Good Practice for the Care of People with Terminal Illness* complements that document.

### **1 • Meeting Individual Need**

Recent changes in the management of health and personal social services seek to organise services on the basis of the needs of the individual and stress the importance of enabling people to receive the care they need whilst remaining within their own community.

The provision of care to meet the different levels of need of those with a terminal illness will be dependent on successful partnership between the statutory health and social providers with a major input from both voluntary and private care sectors. This may involve referral to and from hospice and nursing home at different stages of illness or the provision of specialist palliative care services to the patient in a registered nursing home.

Health Boards should make nursing homes aware of the availability of local palliative care services when they are registered to admit people with terminal illness. The Scottish Partnership Agency for Palliative and Cancer Care (1A Cambridge Street, Edinburgh EH1 2DY) can provide information on services throughout Scotland.

## 2 • Management and Philosophy of Care

We suggest that the registration certificate should not carry any reference to the number of beds for terminal illness. The **number** of beds for those with a terminal illness for which a home is registered should be determined at registration. Patients who develop a terminal illness whilst resident in the home should then be counted as part of that number but there should be sufficient flexibility to allow the number to be temporarily exceeded. However there should be no further admissions of patients with a terminal illness while the proportion of beds is taken up.

When seeking registration for care of people with a terminal illness a nursing home's philosophy of care should have regard to the following objectives:

- To provide a caring, supportive environment promoting independence for as long as possible and ultimately to enable patients to have a dignified and pain-free death.
- To ensure patients, relatives and friends have access to relevant support services.
- To liaise with and introduce the services of other agencies as appropriate e.g. local palliative care services.
- To provide skilled, sensitive care, enabling patients to have the highest possible quality of life.
- To accept and respect the patient's social, emotional, religious, cultural and ethnic needs.
- To respect the right of patients to be informed and so far as possible to participate in decisions about care plans and treatment and if they so wish, for their relatives and friends to be included.
- To recognise the fear of many people that they may die alone and to ensure that this will not happen unless it is the patient's choice.

The nursing home should seek to establish, through the patient's GP, effective liaison with palliative care services to complement the provision of care which is possible from within its own resources. Specialist support for those patients in nursing homes who have a terminal illness, and advice to their carers, may be available from community palliative care nurses and from hospice staff including doctors, nurses and members of the professions allied to medicine.

### **3 • Accommodation**

The Nursing Homes Registration (Scotland) Regulations 1990 require that

*“the person registered shall, having regard to the size of the nursing home and the number, sex, age range and condition of the patients, provide or make, as the case may be, to an adequate standard or level or number the following:*

*accommodation and space for each patient in the home including, where appropriate, day-room facilities separate from sleeping accommodation”.* <sup>(7)</sup>

The patient and/or relatives or friends should whenever possible be able to choose between single or shared accommodation. Accommodation should be available to give patients and visitors privacy. Provision should be made for relatives or friends to be accommodated overnight as appropriate.

### **4 • Furniture and Equipment**

*“adequate furniture, bedding, curtains and, where necessary, suitable screens and floor covering in rooms occupied or used by patients”; and “adequate treatment facilities and medical, surgical and nursing equipment”*<sup>(7)</sup>.

In addition to the furniture and equipment normally provided in a nursing home setting the following items should be accessible for the terminal care beds:

- Variable height bed with tilt mechanism
- Pressure relieving mattress and aids
- Syringe driver
- Suction equipment
- Nebuliser
- Fan

## 5 • Staffing

*“provide adequate professional, technical, ancillary and other supporting staff.”<sup>(7)</sup>*

Arrangements for formal and regular contact with an appropriate palliative care service will be essential in order to provide specialist advice and support to medical and nursing staff.

### A) MEDICAL STAFF

Patients should continue to be in the care of a general practitioner of their choice (thus encouraging continuity of care) who should seek advice from a palliative medicine specialist as appropriate following discussion with the patient.

### B) NURSING STAFF

Within the nursing resource there should be a first level registered nurse, who will have had not less than three months specialist experience of providing care for terminally ill people within the past five years or who has undertaken a relevant course in the care of the dying. This resource person will co-ordinate care planning for those patients and be a facilitator to others within the nursing team. Implicit in care planning for those requiring palliative care is:

- continuity of care
- ongoing supervision of untrained care staff
- increased knowledge and skills of staff at all levels

The registering Health Board will be responsible for determining the levels of qualification and skills mix required of nursing staff in each establishment according to local factors, including size of home and proportion of terminal care beds. The criteria for staffing levels should reflect the degree of dependency of the patients.



### **C) RELATED PROFESSIONAL SERVICES**

There should be ready access to physiotherapy, occupational therapy and chiropody in order to maintain the appropriate degree of mobility and independence of the terminally ill patient. Nutritional and dietetic advice should be available for each patient on an individual basis. Social Work help should be available for patient and family if needed. For all these related professionals appropriate experience of working with or understanding the needs of the terminally ill will be desirable. Arrangements with all these professionals must recognise the importance of a rapid response when working with terminally ill people.

### **D) ANCILLARY STAFF**

Domestic, catering, portering and other ancillary staff, although employed for specific non-direct patient care duties should receive induction and appropriate orientation to the needs of the terminally ill and their relatives or friends. Such staff can bring an additional dimension to the support provided.

### **E) VOLUNTEERS**

Volunteer workers can not only contribute to the services provided but help to maintain contact with the outside world. Their jobs and responsibilities should be clearly defined. It is essential that supervision and accountability are identified.

### **F) SPIRITUAL SUPPORT**

Spiritual support should be available in the home in the normal course of events and in accordance with patients' wishes which may change in the latter stages of their illness. It should be made easy for all patients to have contact with a religious representative.

### **G) EDUCATION**

It is essential that all staff working with the terminally ill should be provided with opportunities to update their skills and to keep abreast of developments in palliative care. Local palliative care services will be a valuable resource for this purpose. Such educational opportunities should particularly take account of the importance of communication and team building skills in the care of the terminally ill.

## **6 • Drugs/Therapy**

The nursing homes should have clear guidelines on responsibility for setting up and monitoring syringe drivers. Nursing staff must be trained and competent in this task.

The Nurse Manager of the nursing home should be responsible for drawing up written protocols on the use of complementary therapies and should be accountable for their use.

## **7 • Suggestions and Complaints**

Staff should be aware that complaints made by a patient's relatives or friends around the time of death are often part of the grieving process. They need therefore to be dealt with in a particularly sensitive way.

## **8 • Deaths and Bereavement**

A clear record should be kept of patient's and relatives' wishes about being present at the time of death and immediately after, and should be available to staff when death is imminent.

Referral to other agencies (most often primary care teams) for bereavement counselling or support should be normal practice where "at risk" families are identified by nursing home staff.

# References

- 1 *Model Guidelines for the Registration and Inspection of Nursing Homes for the Elderly*. Scottish Home and Health Department, 1993.
- 2 *Model Guidelines for the Registration and Inspection of Independent Hospitals and Nursing Homes providing Acute Services*. Scottish Home and Health Department, 1992.
- 3 *The Care of the Dying and the Bereaved in Scotland: "Everybody's Death Should Matter to Somebody"*. A Review and Recommendations by a Working Group of the Scottish Health Service Advisory Council. HMSO, 1991.
- 4 *Care of People with Terminal Illness*. A Report by a Joint Advisory Group. NAHAT, 1991.
- 5 *Cancer Pain Relief and Palliative Care*. Report of a WHO Expert Committee. WHO, 1990.
- 6 *Guidelines for Palliative Cancer Care*. Scottish Partnership Agency for Palliative and Cancer Care and the Clinical Resource and Audit Group of the Scottish Office Home and Health Department, 1994.
- 7 *The Nursing Homes Registration (Scotland) Regulations 1990*. Statutory Instrument 1990. No: 1310 (S.143) Para. 13(2). HMSO.

## Annex 1: Members of the Scottish Partnership Agency for Palliative and Cancer Care Working Group on Registered Nursing Homes and People with a Terminal Illness

No	Mr David Wright ( <i>Chairman</i> )	Director of Quality Assurance and Chief Nursing Adviser, Highland Health Board
	<u>Dr John Bass</u>	Medical Director, The Ayrshire Hospice, Ayr (joined WP Nov 1993)
	<u>Dr J. Davie</u>	Senior Consultant Geriatrician Stobhill General Hospital, Glasgow
	<u>Ms Anne Ferguson</u>	Registered Nursing Homes Association (from July 1992)
	<u>Mrs Lyn Forbes</u>	General Manager, Highland Hospice, Inverness
No	Mr Tom Gibson	Director of Administration Accord Hospice, Paisley (to Oct. 1992)
	<u>Miss Margaret Kindlen</u>	<del>MERD Dundee</del> Education Officer, St. Columba's Hospice, Edinburgh (to Aug 1992). Unit Manager, Craigieknowes Nursing Home, Perth (from Aug 1992)
	<u>Mrs Nan Luney, MBE</u>	Project Nurse Manager, Crosshouse Hospital (joined WP Nov. 1993)
	<u>Dr Maureen Macmillan</u>	Department of Nursing Studies University of Edinburgh
No	Mr Robert Stewart	Registered Nursing Homes Association (to July 1992)
No	<u>Mr Richard Swift</u>	Assistant Chief Area Nursing Officer Dumfries & Galloway Health Board
No,	Mr Clive Winter	NHS in Scotland Management Executive (to Nov 1992)
	<u>Mrs Margaret Stevenson</u> ( <i>Secretary</i> )	Scottish Partnership Agency for Palliative and Cancer Care

## Annex 2: Growth of the Private Nursing Home Sector

Numbers of private nursing homes in Scotland have increased dramatically since 1987 and the rise in the number of homes which admit terminally ill patients has been even more pronounced over the same period (see Table 1 below). Private nursing home proprietors are keen to have their homes registered for care of the terminally ill in order that they can offer a total service to the elderly in their community including those with a terminal illness.

**TABLE 1: REGISTERED PRIVATE NURSING HOMES, SCOTLAND**

<b>Year</b>	<b>Nursing Homes</b>	<b>Beds</b>	<b>Homes taking Terminally Ill</b>
1987	157	4729	29
1991	347	11936	116
1993	427	16477	139

*Source: Information and Statistics Division*

Nursing Homes have more than doubled over the six year period. The total number of beds in registered nursing homes has more than tripled. The number of homes admitting terminally ill patients has increased more than fourfold.

## Annex 3: Demographic Change

Recent demographic changes have resulted in a rise in the proportion of elderly people in the population, with a consequent rise in the incidence of cancer, and this trend is expected to continue into the next century.

**TABLE 2: TRENDS IN THE ELDERLY POPULATION, SCOTLAND 1980-2011**

*Population estimates and projections (000's)*

Age	1980	1991	1995	2001	2011
65-74	465.0	436.5	445.2	433.9	447.0
75-84	226.0	259.2	252.2	268.0	275.0
85+	46.7	69.1	80.0	90.0	102.0
	737.7	764.8	777.4	792.1	824.0

*“From 1991 to the start of the next century (2001), the total number of people over pensionable age will increase slightly by 3%. The number aged 75+ will increase by 10.5%. From 1991 to 2031 the increase will be 44.5% and 64.5% respectively.”* Source: Age Concern Scotland derived from 1991 based GAD population projections, Scotland. General Register Office for Scotland 1992.

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