DAY HOSPICE

REPORT OF A MEETING

of

THE HEALTH SERVICE GROUP

of

THE SCOTTISH PARTNERSHIP AGENCY FOR PALLIATIVE AND CANCER CARE

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Scottish Partnership Agency for Palliative and Cancer Care
1a Cambridge Street, Edinburgh EH1 2DY
Tel 0131 229 0538 Fax 0131 228 2967

CONTENTS

Introduction

This paper is based on a meeting of the Health Service Group of the Scottish Partnership Agency held in May 1995. Guest speakers from two specialist day care services outlined the work of their units and this was followed by a lively discussion which demonstrated considerable interest in day care as an important part of specialist palliative care provision.

The Scottish Partnership Agency is therefore pleased to be able to make the report of the meeting more widely available with the addition of a literature review and directory of hospice day care in Scotland. We hope it will be of interest both to current purchasers and providers and to those considering the development of a specialist day care service.

The Scottish Partnership Agency is grateful to all the authors and to the units they represent, for their contributions to this paper.

DAY HOSPICE

Dr Martin Leiper
Consultant in Palliative Medicine
Roxburghe House, Dundee and Macmillan House, Perth

Chairman, SPA Health Service Group

Hospice but no beds?

When most people think of hospice they imagine a gloomy place with beds. When they actually visit they find not only a positive attitude in the face of adversity but a service which extends care into its local community through home care and Day Hospice. Home care augmenting the primary health care team is the most easily comprehended. Day Hospice is the least understood by both patients, family and professionals. This booklet seeks to explain the role Day Hospice can play in the support of patients and families affected by advanced disease.

Folks won't come in and they won't go home

Day hospice helps accessibility and acceptability. If in-patient hospice care is a first contact for a family it can be very threatening. Admission can be put off until symptoms are intolerable and carers at breaking point. *Not yet. He's not that bad. Does this mean its the end?* If the patient is known to the hospice or palliative care team admission can be less frightening.

Most in-patient palliative care units would seek to relieve symptoms and discharge home at least 30% of all patients. However such patients may become more ill or simply scared to

go home. *I feel safe here.* Day care is a natural bridge for those who need continuing support or are reluctant to break all contact with the palliative care unit.

Day Hospice is growing

There are 15 existing and 2 planned day care units listed in the 1995 Directory of Palliative Care Services in Scotland . They exist in NHS Trusts and in the independent sector.

It's not just a hospice that closes at night

Day hospice is not a cut down version of an in-patient unit. It can meet the needs of patients still at home for weeks or months before they die. It can reach many more families than need an in-patient unit. Most importantly, it can be integrated with services of the primary health care team and community care. It is part of a support system that maintains quality life at home for patients and carers.

What should we call it?

Day Care, Day Hospice, Day Palliative Care, Day Unit, or just St Mungo's? The units described in this booklet thought very carefully about their name and what this means to patients, professionals and the public at large. Day hospice is not just day care meeting social needs but an essential part of a palliative care or hospice service that involves meeting physical and psychological health needs. These patients need the input of specialist health care staff and "day care" does not do justice to the specialist units and the work they do. Day Hospice or Day Unit may therefore be the most appropriate name.

Questions for the future

- Does Day Hospice avoid crisis admissions to hospice or hospital?
- Does Day Hospice enable patients to stay at home for longer?
- Can a Day Unit be used in the evenings for education and support groups?
- Is a Day Unit a base for a symptom control clinic?

All these issues are being explored in Scotland at the moment. In the meantime there are three principles which should be fundamental to the provision of specialist day care:

1. That day care should be accessible by all who could benefit from it.

2. That it should have a multi-disciplinary basis including access to medical advice.

3. That it should be integrated with other forms of palliative care.

THE MACMILLAN RUNCIE DAY HOSPICE

Liz Carruthers
Support and Information Co-Ordinator
Macmillan Runcie Day Hospice
St Albans

The Macmillan Runcie Day Hospice opened in January 1994 following a fund-raising appeal led by CRMF which raised £1,000,000. The purpose built unit provides a base for the Community Palliative Care Service and a Cancer Information & Support Service. It also provides a successful Day Hospice Service for up to 20 patients per day. This paper will describe the work of the multi-disciplinary team and demonstrate how the team works together to help families live and cope with life threatening illness.

Set within the grounds of St Albans District General Hospital in Hertfordshire, the Day Hospice serves a population of 242,000. Day Care opened initially for two days a week and by the end of 1994 this had increased to four days. A pilot programme is currently underway opening the Hospice on a fifth day to younger people with cancer, aimed at the under 55 age group. This service offers a more flexible type of day providing a range of complementary therapies, psychosocial support and peer group discussion for both patients and carers.

The Day Hospice offers skilled nursing care and medical expertise in a warm and supportive environment. The emphasis is on the whole family, recognising that patients, relatives and carers all need support. The family are actively encouraged to use the service of the Hospice Team to provide a source of information, support and comfort. The Day Hospice Staff includes two Medical Advisors, a Day Care Sister, two Staff Nurses and two Day Care Assistants, together with a team of selected bank nurses. We are able to offer our care to up to 25% non-cancer patients with conditions such as MND, Cardio-Myopathy, Aids and Multiple Systems Atrophy.

The services offered in the Day Hospice include medical assessment, pain and symptom control, dressings, physiotherapy, lymphoedema treatment and bathing. A range of complementary therapies, including aromatherapy massage and relaxation are offered by accredited and trained volunteers. Also available are hairdressing and beauty therapy. Activities such as art, craft and cookery are also extremely popular. A key aspect to the success of the day hospice is the opportunity for patients to socialise with other people with potentially life threatening illness providing an opportunity to voice suppressed feelings and emotions. A team of selected and trained volunteers support the professional team and this includes providing a door to door transport service for the patients under the supervision of a Volunteers' Co-Ordinator. A first class hot or cold meal is offered to all patients together with advice on their dietary needs and a small charge of £2.00 per day is made for all the services on offer.

Patients are referred to the Day Hospice by the Primary Health Care Team mostly GPs and Macmillan nurses but some referrals come from our own Information & Support Service, social work and family therapy services. The five Macmillan nurses based at the Hospice cover the North West Herts area and are involved with the patient and family in their own home, offering specialist pain and symptom control, emotional support and liaison with other agencies. A Senior Social Worker offers individual counselling and family therapy,

recognising and addressing the needs of children where a family member has cancer. She also facilitates a teenagers bereavement support group which has been highly successfully.

The work of the Hospice does not end when a person dies. Our Bereavement Service offers free supportive help to bereaved people, not only those bereaved by cancer. Trained volunteer counsellors led by a senior counsellor/social worker see people either at the Hospice or in their home.

Finally, to complement all of these services, our Information & Support Service provides a free and supportive source of up to date information on all types of cancer and its treatment. A drop-in centre is open four days each week or information can be obtained by telephone and letter. Weekly Relaxation sessions are also offered. The service is free and confidential and open to anyone affected by cancer.

It is hoped that this paper demonstrates the holistic care offered to patients living with a life threatening illness and how the multi-disciplinary team based at Macmillan Runcie Day Hospice attempt to enhance the quality of life for patients in the North West Herts area.

STRATHCARRON HOSPICE DAYCARE UNIT

Cathie McRobbie
Daycare Sister
Strathcarron Hospice
Denny

Strathcarron Hospice In-patient, Home Care and Daycare opened in 1981, with Daycare running Monday to Friday since then.

What we do:-

The Daycare Unit provides total patient care (given the constraint of time) in a comfortable, safe environment for patients brought in from home, one or two days per week. Patients are usually referred for daycare by the home care nurses.

We assess each individual's requirement on each visit and provide the appropriate care. This could include bathing, bowel care, wound dressing, physio, O/T, medical consultations, chaplaincy or social work. We liaise with other parties involved in the patients care, e.g. carers at home, district nurses, GPs and home care staff. We also access other professionals who may be able to offer help, e.g. dentist, optician, and chiropodist - all are local, and willing to consult at the hospice.

Transport is arranged to and from Daycare, usually through hospice voluntary drivers. Morning and afternoon tea and lunch are provided.

We have available a variety of activities to be done either by individuals or by groups, eg craft work, garden and greenhouse, indoor bowls, board games, etc. Occasionally we have slide shows, or concerts, with people coming in from outside to entertain the patients. We

have parties, where every patient (maybe as many as 50) is invited, and at Christmas, they can also bring a relative or friend.

At times, we arrange trips in our minibus. We do short trips, 1-2 hours for afternoon tea, or longer trips, 3-4 hours, taking in lunch as well. The patients are usually involved in deciding if we go, and where we go. It is largely the mood of the group which determines the social pattern of each day. We try to be as flexible as possible both in organisation and activities.

We fund raise too. Our big event is the pre-Christmas sale, which has brought in over £2,000 on each of the last two years. The importance of this is that it gives the patients a means of giving something back, and can involve family and friends.

Daycare is host to a variety of students and visitors, including project 2000 nurses, PS2 students, medical students, O/T, Physio, social work, and divinity students, occasionally having come from as far afield as France, Germany and USA.

How many patients do we cater for?

Since 1987 there has been a gradual increase in the number of patients attending. At the end of last summer it was decided to increase the number of places available. The optimum number now, based on staffing level and space available, is 20 patients a day, but this can vary greatly. The reason for this is that there can be last minute cancellations, often as a result of illness and the associated problems our patients suffer from, which mean that attendances cannot be guaranteed. It has therefore become procedure to overbook, in order to maximise the actual number of attendances each day.

Optimising numbers is further complicated by the fact that some patients are physically more dependent than others. The amount of nursing care required is not always proportional to the number of patients. It is, of course, possible to use bank staff if patient dependency is high.

The admission and discharge policies are as follows:-

Admissions:- Referrals should come from GPs or Consultants in the usual way. Existing patients already on Home Care or in the ward may be referred by medical staff or Home Care Sisters. Non-malignant patients are often referred specifically for Daycare treatment only. These have to be assessed and accepted by the Hospice Consultant.

Patients may be offered one or two days per week at Daycare depending on their situation. It should be pointed out from the outset that this arrangement should and could be flexible i.e. the number of attendances per week may be adjusted according to individual need and the Hospice's workload at the time.

Discharges:- Patients may be discharged from Daycare for the following reasons:

a) death or transfer to another service
b) moving away from the area
c) unable to travel any more
d) improvement or "plateau" reached in condition so that Daycare becomes neither desired or useful
e) difficulty coping with excitability or irritability in a patient, causing undue disruption and distress to others

Who is involved?

On any normal day, 2 x RGNs, 2 x Auxiliaries, an O/T, a Physio, a Craft Worker and a Secretary, (who co-ordinates the voluntary transport), make up the staff complement, assisted by 2 domestics and 2 volunteers.

A doctor from a local practice in Denny attends in the afternoon, and is available to see any or all of the day patients. A social worker and a chaplain are available to anyone requiring their particular skills.

In addition Home Care Staff, (or Macmillan Nurses) often continue their involvement with day patients in their homes, as the carer often needs support just as much as the patient.

To Sum Up

Success at Strathcarron Daycare Unit is not the product of pure chance.

This success requires a lot of effort on the part of Daycare staff and volunteers to create the atmosphere conducive to patients feeling comfortable and relaxed, and having a sense of belonging. It depends primarily on good communication, teamwork, and liaison between all parties involved in patient care.

The right mix of staff is also important, to provide the complete spectrum of care based on the individual needs of the patients, ranging from those who are there mainly for social contact, right through to those requiring total patient care.

DISCUSSION

The contributions from Cathie McRobbie and Liz Carruthers were followed by discussion in which the following issues were raised:

The clinical input to day hospice care makes it different to day care. Sometimes referring GPs do not appreciate this. Where medical input is provided by local GPs on a sessional basis this can create problems of one GP seeing another GP's patients. Social Work input is necessary but seeking social work department funding carries the danger of service users being means tested.

Even with hospice day care provision it is extremely difficult to provide sufficient support for someone to stay at home. Experience in some parts of Scotland has been that social work departments were not willing to arrange complex care packages to underpin district nursing for terminally ill people.

Palliative day care in a sparsely populated rural area could be provided by a day care team going to different places each day.

Depending on geography and density of population **1 day care place per 10,000 population is recommended.** Optimal size was thoght to be 20 places. The number of neurological patients accepted often has to be restricted because of their high dependency.

Transport and travel time is not such a problem as with geriatric day care because it is provided almost entirely by volunteer drivers collecting only a small number of patients. Half an hour however is suggested as the maximum desirable travel time.

Discharge policy needs to be clear and discussed with the patient and family. 2 monthly reviews involving the patient and all professionals are suggested. Attendance could not go on indefinitely. At Strathcarron a core group of patients who had been attending for a longer period were found to be helpful to new patients and to provide stability to the group.

LITERATURE REVIEW

The Role and Development of Palliative Day Care

May Grafen
Macmillan Nurse
St Johns Hospital
Livingston

Palliative day care is a relatively recent innovation with the first purpose built day hospice opening in 1975 at St Lukes Hospice in Sheffield. From this beginning, there are now over 200 day hospices throughout the UK and Ireland. These are either free-standing or attached to hospice in-patient units or teams. (Hospice Information Service, 1994)

Wilkes et al (1978) study describes in depth the first 26 months of this first day hospice for patients with cancer and the chronic sick. The study concludes that the support provided was of great importance to both patient and family with two-thirds of the patients said to have benefited from improved symptom control. Despite demonstrating a general improvement in care, there was no evidence that it would shorten the final stay in hospital. The day hospice was a purpose built adjunct to the in-patient hospice and opened five days per week from 10am until 3pm. Services on offer were physical care, physiotherapy, occupational and recretional therapies. The number of patients averaged between 10 and 17 per day. Patients with advanced cancer were accepted as soon as possible after referral with no limit on duration of attendance.

Places allocated to the chronic sick were limited to a total of 20, with once weekly attendance for 8 weeks then further review between 9-12 months later. Rehabilitation to prolong independence for as long as possible was the ultimate goal. Half the patients with cancer had obvious social and emotional needs, while a quarter needed general nursing care and a quarter effective control of pain.

Eve and Smith (1991) carried out a study whose main objective was to describe and quantify palliative care services in Britain and Ireland. Within day care, two main models of care were described - a social and a medical model. However, this study did not determine the prevalence of each. Of the 127 respondents with palliative day care units, 40% did not have a doctor available at each session. No correlation was found between the presence of a doctor and the accessibility of an attached in-patient unit, or between the

number of days open per week. 82 units also cared for patients with motor neurone disease and a surprising number of 56 offered places for people with AIDS, while an unstated number would also care for people with other diagnosis.

With an increasing emphasis being put on day care, a qualitative study was undertaken for Help the Hospices by Faulkener et al (1993). Its aims were to identify areas of good practice and the common problems encountered in day care units, whilst reviewing educational objectives for those involved in day care. The general ethos of the 12 day care units who participated in the study echoes that of Wilkes (1978). The number of days units open between Monday and Friday varied with only 2 opening for 5 days, and the majority open for 3-4 days. None of the respondents offered a 7 day facility. Level of opening was determined by perceived local need and resources available to keep the day unit operational. The numbers of patients attending varied between 3 and 17; 11 of the 12 units had nurses routinely present, but only 5 had regular doctor presence. There was a wide range of ancillary staff, but not available in every unit.

Faulkener et al (1993) demonstrated that for day care the main objectives encompassed clinical surveillance, respite care, social stimulus and creative activities. The priority given to each of these objectives varied significantly between units. Questions arise around the lack of any admission and discharge policy. Many patients had been attending for a number of years on an open ended basis with no formal review, however Doyle et al (1993) recommended defined criteria for admission and a review policy around 12 weeks because some patients can unexpectedly go into true remission.

Faulkener et al (1993) showed that resources varied enormously. There was no common policy on either staffing levels or on facilities available. Contrary to previous studies, medical input appeared more likely if the day care facility was attached to an in-patient unit, but was dependent on available space for consultation. It was shown that where a doctor was available, there was the good practice of regular assessment and close GP negotiation. Furthermore Sharma et al (1993) demonstrated in a small study that medical input was necessary. This input was supportive to nursing staff and also reassured patients.

In units where there was no volunteer co-ordinator, and the nurse in charge organised everything, there was more likely to be fragmented nursing care due to fragmentation by multiple duties. There was no common policy on minimal training and skills for those who provide day care.

"Clear criteria for day care need to be set and training programmes devised so that criteria may be met and high standards maintained" (Faulkener et al, 1993)

The literature on palliative day care demonstrates that although day hospices vary greatly in their structure and process, many of the initial concepts described by Wilkes continue. However, no common policies on staffing levels, facilities or admission/discharge criteria exist. Where medical input is available, assessment and GP liaison is improved. Nursing care was seen to be fragmented in areas where the nurse in charge had multiple duties. On the whole, carers needs are not addressed.

"Palliative care needs to include both the patient and family because the needs of the family may exceed those of the patient" (Higginson et al, 1990)

The provision of palliative day care for people with non malignant disease is limited. Where it is available, the emphasis is on improving quality of life for both the patient and carer.

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DAY HOSPICE PROVISION IN SCOTLAND 1995

Information extracted from the Directory of Palliative Care Services in Scotland 1995, published by SPAPCC in conjunction with the Health Education Board for Scotland. Copies of the Directory can be obtained from SPAPCC 1a Cambridge Street, Edinburgh EH1 2DY. Please send £1 to cover postage and packing.

ABERDEEN

Roxburghe House
Tor Na Dee Hospital
Milltimber
Aberdeen AB1 0HR

Tel: 01224 681818 Ext 55641

Day Unit open:
Monday - Friday 10am - 3pm

AIRDRIE

St Andrews Hospice
Sisters of Charity
Henderson Street
Airdrie ML6 6AS

Tel: 01236 766951

Day Unit open:
Monday - Friday 10.30am - 3.30pm

AYR

The Ayrshire Hospice
35 Racecourse Road
Ayr KA7 2TG

Tel: 01292 269200

Day Unit open:
Monday - Friday 10am - 4pm

BRECHIN

Macmillan Day Care Unit
Stracathro Hospital
Brechin

Tel: 01356 647291

(To open Autumn 1995)

EDINBURGH

St Columbas Hospice
15 Boswall Road
Edinburgh EH5 3RW

Tel: 0131 551 1381

Day Unit open:
Monday - Friday 10am - 3pm

Fairmile Marie Curie Centre
Frogstone Road West
Edinburgh EH10 7RD

Tel: 0131 445 2141

Day Unit open:
Monday, Tuesday, Wednesday and Friday
9.30am - 2.30pm

GLASGOW

Hunters Hill Marie Curie Centre
1 Belmont Road
Springburn
Glasgow G21 3AY

Tel: 0141 558 2555

Day Unit open :
Monday - Friday 10am - 3.30pm

Prince & Princess of Wales Hospice
73 Carlton Place
Glasgow G5 9TD

Tel: 0141 429 5599

Day Unit open:
Monday - Friday 10.30am - 3pm

St Margarets Hospice
Sisters of Charity
East Barns Street
Clydebank G81 1EG

Tel: 0141 952 1141

Day Unit open:
Monday - Friday 10am - 4pm

GREENOCK

Ardgowan Hospice
12 Nelson Street
Greenock PA15 1TS

Tel: 01475 726830

Day Unit open:
Tuesday - Friday 10.30am - 3.30pm

INVERNESS

Highland Hospice
Ness House 1 Bishops Road
Inverness IV3 5SB

Tel: 01463 243132

Day Unit open:
Tuesday - Thursday 9.30am - 3.30pm

JOHNSTONE

St Vincents Hospice
Midton Road
Howwood
Johnstone PA9 1AF

Tel: 01505 705635

Day Unit open:
Tuesday and Thursday 9.30am - 3.30pm

LIVINGSTON

St Johns Macmillan Centre
Howden
Livingston EH54 6PP

Tel: 01506 419666

(To open Winter 1995)

MOTHERWELL

Dalziel Unit
Strathclyde Hospital
Airbles Road
Motherwell ML1 3RB

Tel: 01698 258800 Ext 247

Day Unit open:
Monday - Friday 9am - 5pm

PAISLEY

Accord Hospice
Hospital Grounds
Hawkhead Road
Paisley PA2 7BL

Tel: 0141 889 8169

Day Unit open:
Monday - Friday 10.30am - 3pm

STIRLING

Strathcarron Hospice
Randolph Hill
Fankerton By Denny
Stirling FK6 5HJ

Tel: 01324 826222

Day Unit open:
Monday - Friday 9.30am 0 4pm

PERTH

Macmillan House
Springland Isla Road
Perth PH2 7HQ

Tel: 01738 639303

Day Unit open:
Monday - Friday 9am - 4pm

NATIONAL ASSOCIATION OF HOSPICE/PALLIATIVE DAY CARE LEADERS

Provides a network for Day Care Leaders, both locally and nationally, through education and support and promotes good practice within the membership. Organises an annual meeting and produces a newsletter.

Senior Nurse & Chair:
Mrs P McDaid
Michael Sobell House
Mount Vernon Hospital
Rickmansworth Road
Northwood
Middlesex HA6 2RN
Tel: 01923 844302

Secretary:
Linda Watts, Thames Valley Hospice
Tel: 0175 384 2121