

ENHANCING THE DAY THERAPIES SERVICE FOR PEOPLE WITH PALLIATIVE NEUROLOGICAL CONDITIONS



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Enhancing the day therapies service for people with palliative neurological conditions.

Summary

The current day therapies model for patients with palliative neurological conditions does not optimally support their needs. This project proposes an additional day per week at Day Therapies Service (DTS), which will include regular visits from key NHS health professionals and will increase the ratio of hospice staff/volunteers to patients to assist them during their day. For an initial set up fee of £2273 [appendix 1] and a cost of £21,613 for the first year [appendix 2], this innovation will decrease the need for people with significant physical and functional limitations to travel to multiple clinic appointments, allow all day therapies patients across the whole service to receive more individualised and tailored proactive care whilst at Day Therapies, increase capacity across DTS and has the potential to increase productivity of NHS staff.

As part of the 2020-2023 St Columba's Hospice strategy, the hospice is proposing increasing community services and access to palliative care for people with non-malignant conditions; at all stages of their illnesses. If successful, the funding for this additional service will not come from new investment, but from redeployment of current St Columba's staff. Therefore, **no additional funding will be required to meet the costs in appendix 1 & 2** and there will be no recruitment costs.

The purpose of this economic assessment is to identify the full costs and benefits that this additional DTS day would bring and to demonstrate the benefits for patients, families, the NHS and St Columba's Hospice. I will discuss this through a Pathways to Outcomes model.

Introduction

People with progressive neuromuscular degenerative illnesses (such as Motor Neurone Disease [MND], Progressive Supranuclear Palsy [PSP], Multi-systems Atrophy [MSA] and Corticobasal Degeneration [CBD]) have a high level of physical impairment and need full assistance with personal care, moving their limbs, eating, drinking and communicating.

UK hospices use a validated and reliable tool called the Australia-modified Karnofsky Performance Status Scale (AKPS) to measure peoples' functional abilities [1] and these people score between 20-40% which means they are *'almost or totally chair/bedfast and require extensive nursing care by professionals and/or families.'* This is in comparison to the other group of people who attend DTS who score between 60% and 80%, indicating they are *'mostly able to care for themselves and carry out some normal activities.'*

Currently, a mix of people with different AKPS scores attend on the same day. In the proposed model, all current patients with AKPS of 20 -40% will move into the new day and all new patients referred to the service will be assigned a day based on their AKPS score at assessment. The new day will be called an 'assisted' day and the current days called 'enabling' days. For full detail as to the current structure of DTS, see appendix 3.

The addition of an 'assisted' day to compliment the two current 'enabling' days would provide the following key benefits:

- Increased capacity by 50% for 'enabling' day patients (AKPS 20-40%) from 1000 spaces per year to 1200 spaces per year
- Increased capacity by 20% for 'assisted' day patients (AKPS 60-80%) from 200 spaces per year to 300 spaces per year.

- The potential to increase productivity for NHS professionals by decreasing travel time by 1hr per week per patient seen at the hospice rather than at a home visit

These benefits, and others, are discussed further in a later section and presented in full in appendix 4.

The background and context of this project

This proposal is in response to managing the DTS for 2 years and identifying the specific needs that this group of patients have. However, it is also a way to address the aims in several current key strategic documents. The Scottish Government is currently aiming for ‘Access to palliative and end of life care to be available to all who can benefit from it, regardless of age, gender, diagnosis, social group or location. People, their families and carers will have timely and focussed conversations with appropriately skilled professionals to plan their care and support towards the end of life, and to ensure that these accord with their needs and preferences’.[2] This innovation delivers this national vision.

In recent publications, both The Progressive Supranuclear Palsy Association (PSPA) and The National Institute for Care and Excellence (NICE) guidelines on the assessment and management of MND recommend early access to palliative services for symptom management and advanced care planning and regular access to multidisciplinary team (MDT) [3,4]. This new service delivers these recommendations.

This proposal clearly meets the NHS Lothian key targets in their current strategic plan as their vision for care by 2020 [5].

CURRENT NHS SERVICES	FUTURE MODELS OF CARE
Geared towards acute / single condition	Designed around people with multiple conditions
Hospital - centred	Located in local communities and their assets
Doctor dependent	Multi-professional and team - based care
Episodic care	Continuous care and support when needed
Disjointed care	Coordinated and integrated health and care
Reactive care	Preventive and anticipatory care
Patient as passive	Recipient informed, empowered patients
Self-care infrequent	Self-management / self-directed support
Carers undervalued	Carers are supported as full partners

For people with neurological palliative conditions, their care throughout the NHS system is often aligned with the left-hand column. The proposed assisted DTS day meets all of the aims in the right - hand column and is demonstrated in the following 2 examples:

Case study 1

Mrs J’s husband heard about DTS through a support group and asked her GP to refer. She has had a diagnosis for 4 years and lost ability to walk 2 years ago. She is not having regular review by neuro services as appointments keep getting postponed due to the postponement of the hospital relocation and she hasn’t seen neuro Clinical Nurse Specialist (CNS) in over a year. She was also diagnosed with breast cancer this year. She was given a wheelchair by NHS 2 years ago but then was discharged. This wheelchair now does not give her adequate support; she has a sore neck as the muscles of her neck and head have weakened and her chin is resting on her chest. This limits her

ability to swallow, make eye contact and speak. She sees Speech and Language Therapy at home. Mr and Mrs J both feel unsupported and alone. He is worried about the future and what will happen as she gets less well, but has no one to speak to about this.

The new service model will:

- Support regular reviews by wheelchair services and neurology CNSs during their attendances at DTS and identify problems in a proactive way
- Allow regular MDT communication
- Give Mr J opportunity to speak with hospice staff and neuro CNS to start thinking about how things will be in the future
- Give Mrs J some emotional support through regular attendances and the building of relationships with staff, volunteers and other attendees
- Give Mr J choice and control over his involvement at DTS – to attend when he wants to be involved in appointments or to have some respite time

Case study 2

Currently, Mr A attends day therapies fortnightly with his wife. His wife drives him in a wheelchair adapted car, which she can manage to the hospice, but finds it a stressful experience driving across the busy city of Edinburgh to hospital appointments where there are often parking difficulties and then long distances to push him in his wheelchair once they have arrived. There are also often long waits once at the clinics and he is not able to change position in his wheelchair without a mechanical hoist. He has to attend hospital for spasticity clinic, and wheelchair adaptations, although recently, wheelchair reviews have been at day therapies. This has been better for Mr A but time consuming and tricky for the professionals to coordinate. Mr A was recently admitted to the St Columba's Hospice in-patient unit to commence a new anti-spasticity medication. The neurology nurse visits them at home but only every 4-5 months. There are often delays in a problem being identified in day therapies and the professional being able to see Mr A.

Under the new service model Mr A will:

- Come to the hospice on a fortnightly basis, where he could see the NHS health professionals at regular scheduled intervals. Mrs A finds the hospice easy to get to from home and there is accessible parking and only a short distance to push her husband in his wheelchair and access to hoists
- Regularly see neurology nurse and problems such as his spasticity could be attended to in a preventative and anticipatory way and it is possible that the in-patient admission may not have been necessary or the stay shorter as he would have had more frequent neurology nurse appointments

Pathways to Outcomes

The pathways to outcomes model below explain the inputs, outputs and outcomes for this proposed service.

Inputs:

- **Direct**
- Management set up - stakeholder engagement, questionnaires, learning how to conduct economic evaluation and writing proposal (£1,745)
- Additional clinical & admin staff: 0.55WTE (mixed band. £21,613 Year 1)
- Additional volunteers & drivers: 0.4 WTE, already recruited and employed by the hospice (no additional cost)
- Travel costs (£630 fuel for wheelchair accessible vehicle)
- Catering, heating and lighting (no additionality)
- Volunteer training (no additionality)

Salary costings provided by St Columba's Hospice finance department, July 2019.

- **Indirect**
- NHS Professionals – 6 visits per year (cost benefit not considered as part of this project)

Outputs: For assisted patients, an extra day therapies day will:

- Provide tailored services
- Regular NHS reviews by speech & language therapy, clinical nurse specialists and wheelchair services
- Extra physio assessment and reviews
- Increase staff/volunteer to patient ratio (from 1:3 to 1:2 staff and with trained volunteers 1:1)
- Increase patient transport capacity
- Upskill volunteers (cost saving of £9,410 by moving these roles from 3 AfC band 1 staff (5 hours each) to 3 volunteers)

Outcomes:

- **Assisted patients and families**
- Proactive and preventative response to symptoms by NHS services
- Decreased travel to multiple appointments

- Carer respite
- Groups/activities/therapies tailored to emotional need and functional ability
- More individual time with staff (1hour extra of 1:1 time per session)
- Possible downward comparison [6]
- **Enablement patients**
- Increased time with staff for symptom management, emotional support and rehabilitation (0.4hours extra of 1:1 time per session)
- Less downward comparison [6]

Staff outcomes

- Anticipated decreased travel time for NHS professionals; increased productivity and efficiency
- Improved NHS/hospice multidisciplinary team (MDT) working
- Sharing of staffs' knowledge and skills and increased professional learning and development

St Columba's Hospice

- Increased capacity across DTS, 1000 to 12000 enabling spaces and 200 to 300 assisted spaces
- A model of excellence for neurological palliative illnesses
- Potential research and partnership funding opportunities (e.g. with MND Scotland)
- Maximise positive publicity – national/ international conferences
- Implementation of Hospice's strategic aims for non-malignant illnesses and NHS Lothian and Scottish Governments' strategic visions for palliative care
- Full implementation of NICE guidelines for MND and PSPA recommendations

Next steps following implementation of this service

- Invite spasticity clinic to be part of MDT
- Monetise the cost of NHS staffs' time (SALT, wheelchair services) attending the assisted day to see several patients in a single day compared to several home visits
- Continue to collect data on DTS staff's indirect patient contact time (letters, emails and phone calls) and compare old and new services – expected decrease in this, which will demonstrate productivity and efficiency benefits
- Compare admissions and length of stay for assisted patients between old service and new service – expectation is that admissions and length of stay may potentially decrease. Monetise this saving.
- Use a qualitative approach with patients and families to evaluate their experience of using the new service

- Repeat survey monkey questionnaire to evaluate NHS staff opinions of new service
- Present at national conferences such as annual NHS Scotland event, Hospice UK, Association of Palliative Day Services, Scottish Palliative Care Conference
- Consider replication of this service model to other patient groups, for example heart failure and respiratory reviews when patients attend the breathlessness group
- Explore possible external funding sources (e.g. MND Scotland) for the future of this service

This case study was completed by Yvonne Whitehouse, Day Therapies Manager, St Columba's Hospice in 2019. Yvonne successfully completed an RCN leadership development programme commissioned by a consortia of four hospices in Scotland. The programme was designed to empower professionals to understand the principles of economic assessment and apply them in their practice in order to demonstrate the value of, and continuously transform, their services.

The programme is endorsed by the Institute of Leadership and Management.

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References

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<https://pspassociation.org.uk/app/uploads/2018/06/PT009-13-6-Pathway-Guide-web-2013.pdf>

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4. National Institute of Clinical Excellence guideline 42 (2016). Assessment and Management of Motor Neurone Disease

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<https://org.nhslothian.scot/OurHealthOurCareOurFuture/Documents/OurHealthOurCareOurFuture-NHSLothianStrategicPlan2014-2024.pdf>

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6. Soundy, A. & Condon, N. (2015) Patients experiences of maintaining mental well-being and hope within motor neuron disease: a thematic synthesis *Front Psychol.* 6: 606

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4428059/> Accessed on 7/11/19

7. Multipliers used in ward settings to identify correct nursing to patient ratios

http://shelfordgroup.org/library/documents/130719_Shelford_Safer_Nursing_FINAL.pdf

Accessed on 7/11/19

Appendix 1: Set up costs

Identify	Additionality and Apportion	Full costs
60 hours of band 7 time (running total kept of how many hours I have spent on this)	100% additionality – have been paid for these extra hours Attending RCN course, conducting survey monkey and interviews, writing up project	£29.91/hour x 60 hours £1793 (Salaries and on costs as provided by St Columba's Hospice finance dept July 2019)
Estimated 2 hours per week for 2 months before service commences to continue set up	0% additionality - this will be within current WTE hours	£29.91x2hrsx8wks £478
3 volunteers – training and recruitment process already part of the hospice	0% additionality	Volunteers are currently hospice volunteers so no recruitment costs. No change to PVG requirements
Time from hospice staff to train volunteers	0% additionality	Cost absorbed by hospice as staff are already delivering this training programme to ward staff and have agreed DTS volunteers can attend. Volunteers don't charge mileage costs for attending training
Building – lighting/heating	0% additionality	Hospice will already be open and heated
		Total set up cost: £2273

Appendix 2: running costs of year 1 (2020-2021) of the 'assisted' day

Identify	Additionality	Apportion	Full costs (Salaries and on costs provided by St Columba's Hospice finance dept July 2019)
Catering for potentially 3 patients (others will have gastrostomies or bring own specialised diets)	0% additionality	Absorbed cost as kitchen already over-produces meals.	£0
Transport – fuel for the hospice wheelchair accessible vehicle.	100% additionality	1 return journey of up to 30miles/week @42p/mile £12.60/week for 50 weeks	£630
Using volunteers instead of band 1 staff to provide additional support to assisted day	100% additionality	No travel claimed Training costs absorbed No recruitment costs	0.4WTE cost £0
An extra 0.2 WTE AfC band 2 auxiliary nurse/admin assistant (figures based on salary of current band 2 in DTS post)	100% additionality	inc 14% pension and 13.8% employer NIC Hourly total cost £12.40	0.2WTE cost £4,836
An extra 0.2 WTE AfC band 4 physiotherapy assistant (figures based on salary of current band 4 in DTS post)	100% additionality	inc 20.9% pension and 13.8% employer NIC Hourly total cost £15.50	0.2WTE cost £6,045
An extra 0.2 WTE AfC band 5 nurse (to be redeployed therefore current pay point unknown, so mid-point used, £26,303 and pension contribution estimated.)	100% additionality	inc estimated 14% pension and 13.8% employer NIC Hourly total cost £17.23	0.2 WTE £6,719
Band 7 physio assessment/review time: 24 patients per year. 3 hours face to face per patient over a 6 month attendance. Note writing/MDT liaison time for physio appointments. 20mins per session= 1 hour over 6 month attendance	0% additionality – will come from current working hours 24 patients x 4 hours each = 96 hours	inc 20.9% pension and 13.8% employer NIC Hourly total cost £29.91 96hrs/year	0.05WTE £2,871
			Total staff running costs: £20,471+2.5% inflation as service will start in 2020 £20,983
			Total running costs in year 1: £21,613

Appendix 3: Structure of DTS

DTS is currently staffed 3 days per week; AfC band 7 physiotherapist/manager, a band 6 nurse specialist, a band 4 physiotherapy assistant and a band 2 auxiliary. 2 of the days are 'enabling days' and one day of assessments, outpatient reviews, family meetings, indirect patient contacts, home visits and management/administration.

On the 'enabling' days there are 2 volunteers. The volunteers have some manual handling training to assist people that can walk, but no specific healthcare training.

The service can see up to 12 patients each day and there is an aim to have no more than 2 assisted patients on each day. The 10 enablement patients attend for 12 weeks and to date, there have not been clear discharge plans for the assisted patients.

The proposed 'assisted' day staffing would be for AfC band 5 nurse, band 4 physiotherapy assistant and band 2 auxiliary with 3 volunteers trained in using the stand hoist and assisting people with meals and drinks. This day would have 6 patients per day who would attend fortnightly for 6 months initially. They would be reviewed by band 7 physiotherapist every 6 weeks and NHS staff regularly throughout first 6 months. They then may be discharged or move to monthly reviews depending on need and service capacity.

A current 'enabling' day involves group seated and standing exercise (where neuro patients have passive stretches if there are staff available), a physical activity group such as gardening or baking, music therapy or art class, complementary therapy and 1:1 sessions on fatigue, breathlessness, medicines management or goal setting. For someone that is unable to move or speak, they are observers of these sessions rather than active participants and sessions such as discussions around nutrition during the baking group is not relevant for someone who is unable to take food orally.

The new 'assisted' day would allow each patient to have passive stretches, assisted breathing exercises and massage and for the day to be more planned with them and their family and focussed much more around their interests or needs – perhaps someone reading the paper with them or doing reminiscence, music or legacy work. Lunch would not be such a large part of the day, and those who could eat would be able to enjoy a meal with staff or volunteers. The increased ratio would allow all patients to be outside in their wheelchairs if they wished.

Appendix 4.1: Quality benefits – ‘Assisted’ patients (AKPS 20-40%) and their families

Benefit type	Additionality	Do you have own data for value of benefit?	Are you able to express it in terms of service use / time spent?	Are there proxy data published elsewhere/ what are next steps?
<p>Increased ratio of staff to patients from 1:3 to 1:2, and with the addition of volunteers 1:1</p>	<p>Increased 1:1 time with staff for stretches/ positioning changes/ to practice with communication aids – improved patient experience.</p> <p>Activities more tailored to their abilities – for example compiling their playlist for life with staff/ volunteers rather than listening to other people play instruments in music therapy.</p>	<p>‘bottom-up’ approach, observations for 2 weeks of staff time spent with neuro pts (volunteers currently don’t work with this patient group)</p>	<p>Based on observations, each assisted pt currently has 3.5hrs with staff. New service: each would have 4.5hrs with staff/vol</p> <p>Addition of clinical volunteers – would be supernumery but add to enhanced patient experience Each patient would have 1 extra hour with staff/volunteer per session for therapeutic work</p>	<p>No current staffing level recommendations published for day hospices. For interest I looked at The Safer Nursing Care Tool [7] which recommends 1.72 WTE nurse to bed ratio for this patient group in a hospital ward</p>
<p>All appts in one place that carers could choose to stay for if they wished. Less travel to other appts</p>	<p>n/a</p>	<p>Mr A (in case study) attended 2 appointments at hospital spasticity clinic and had 3 wheelchair reviews at DTS.</p>	<p>2 days of stress for Mrs A and discomfort for Mr A at clinic would be eliminated if clinic reviewed at DTS. W/C therapist only saw one pt (Mr A) at reviews as no coordinated approach for this pt group. No measured/ monetised data for this as this occurred prior to this project.</p>	<p>no</p>

Appendix 4.2 Quality benefits - 'Enabling' pts (AKPS 60-80%)

Benefit type	Additionality	Do you have own data for value of benefit?	Are you able to express it in terms of service use / time spent?	Are there proxy data published elsewhere/ what are next steps?
Increased time with staff	Increased senior clinical staff time for patients with complex advanced care planning needs, or complex oncology/respiratory physio needs	Currently 9hours of staff time (16-7 for neuro patients) divided by 10 patients=0.9hrs each. New service:16 hours of staff time per session divided by 12= 1.33hours each	Each patient would have an increase of 0.4hrs per session for symptom management, medicine reviews, fatigue and breathlessness management	The Safer Nursing Care Tool recommends staff to patient ratio of 0.99 WTE nurse to bed for this patient group

Appendix 4.3 Quality benefits - staff

Benefit type	Additionality	Do you have own data for value of benefit?	Are you able to express it in terms of service use / time spent?	Are there proxy data published elsewhere/ what are next steps?
Increased direct patient contact time for DTS staff with both groups of pts	no	Survey monkey results – over half reported a benefit being new MDT working - increased learning across teams Potential for staff retention Potential to increase staff job satisfaction	no	Repeat survey monkey questionnaire once service is established

Appendix 5 Innovation benefits – staff

Benefit type	Additionality	Do you have own data for value of benefit?	Are you able to express it in terms of service use / time spent?	Are there proxy data published elsewhere/ what are next steps?
Joint working	First example of joint working of this kind between a hospice and NHS in Lothian Upskilling – enhanced personal and professional development Opportunities to present at conferences	UK examples of MDT clinics being hosted in hospices but not integrated into Day Therapies days. 50% of respondents in questionnaire said it would be better than current service.	no	Mountbatten Hospice MDT clinic first year feedback positive from patients and staff Plan to repeat survey monkey with NHS staff and assess patient and family satisfaction once service implemented
New role for volunteers. First SCH volunteer auxiliary training programme to start in 2020 for the inpatient unit.	Opportunity to develop this into DTS - cross upskilling, collaboration and innovation across the hospice	Volunteer roles until now have been non-clinical and the in-patient unit are now training volunteers into nurse auxiliary roles	no	Impact of volunteers in clinical roles will be assessed by the Volunteer Services Team across IPU and DTS once roles are established.

Appendix 6.1 Productivity benefits – staff

Benefit type	Additionality	Do you have own data for value of benefit?	Are you able to express it in terms of service use / time spent?	Are there proxy data published elsewhere/ what are next steps?
Decreased indirect contact time (phone/email/referrals) for DTS staff and NHS staff	no	'bottom-up' approach, observations for 2 weeks of staff time spent with neuro pts	Currently 45mins per 'assisted' patient	Continue to monitor indirect patient contact time in new model and compare with old model - expectation that there will be a productivity benefit
Less travel time to HVs for NHS staff – based on survey monkey results	no	Survey monkey results	50% said it would decrease travel time by 30mins-over an hr per pt. If one NHS staff saw 2 patients at DTS, decrease of approx. 45mins of travel per pt – 90mins total. Staff reported they spent 1-1.5hrs face to face per pt so 2 pts at DTS could increase their capacity by 1 extra pt elsewhere in that week	Measure and monetise this once service is established.

Appendix 6.2 Productivity benefits – St Columba’s Hospice

Benefit type	Additionality	Do you have own data for value of benefit?	Are you able to express it in terms of service use / time spent?	Are there proxy data published elsewhere/ what are next steps?
Service capacity	Enabling patients	Current service statistics	Currently 1000 spaces per year (20/wk x 50weeks.)	Would increase to 1200 spaces per year (24/wk x 50weeks.) 20% increase
Service capacity	Assisted patients	Current service statistics	Currently 200 spaces per year (4/wk x 50 weeks.)	Increase to 300 spaces per year (6/wk x 50 wks) 50% increase
Cost benefit in upskilling volunteers into clinical roles	3 volunteers for 5hrs/day on the assisted day=15hrs	no	0.4WTE	Training volunteers rather than using staff -cost saving of midpoint AfC band 1 for 15hours/wk Saving of £9,410 in year 1

Appendix 7 Prevention benefits

Benefit type	Additionality	Do you have own data for value of benefit?	Are you able to express it in terms of service use / time spent?	Are there proxy data published elsewhere/ what are next steps?
<p>Increase in proactive symptom management</p> <p>Potential admission avoidance and decreased length of stay</p>	no	<p>Clinical example: patient needing neuro CNS/Physio/wheelchair review for medication and wheelchair adaptations. Multiple emails and phone calls followed by inpatient admission. In new model, face to face with patient and MDT at 'assisted' day visits.</p>	<ul style="list-style-type: none"> -Potential for admission avoidance or decreased length of stay -Quicker wheelchair adaptations -Joined up, proactive care 	<p>Measure admissions and length of stay from new service and compare to current</p>