Innovating for Improvement

Palliative Pain Management Programme

St Joseph’s Hospice
About the project

Project title:
A Palliative Pain Management Programme (PPMP)

Lead organisation:
St Joseph’s Hospice, London.

Partner organisation(s):
Cicely Saunders Institute, King’s College London.

Project lead(s):
Caroline Quilty, RD, MSc
Gemma Wardle, BSc, MCSP
Karen Piper, BSc, MA, Post MA Dip

Contents

About the project ........................................................................................................ 2
Part 1: Abstract ........................................................................................................ 3
Part 2: Progress and outcomes .................................................................................. 4
Part 3: Cost impact ..................................................................................................... 11
Part 4: Learning from your project .......................................................................... 12
Part 5: Sustainability and spread ........................................................................... 17
Sustainability ............................................................................................................... 17
Spread .......................................................................................................................... 18
Appendix 1: Resources and appendices .................................................................. 20
Part 1: Abstract

Our innovation was to pilot a pain management programme (PMP) to support patients at St Joseph’s Hospice. The hospice cares for people aged over 18 years who have a life-limiting or terminal illness, a group which would ordinarily be excluded from chronic pain programmes in mainstream services.

33 patients were referred for the service, resulting in four group cohorts and three one-to-one interventions completed. 14 patients finished the programme. Outcomes were used to measure physical, emotional and social domains of health. Goal Attainment Scaling was used and qualitative feedback gathered.

The innovation was limited by small numbers of referrals and high attrition rates. The quantitative outcomes did not improve, but analysis was limited by the small sample number (n=14). However, the group was rated as ‘excellent’ and ‘useful’ by the majority of completing patients.

The programme has raised the profile of the Therapies Services team and its capacity to treat complex pain. Within our team we have increased awareness of the complexity of pain in a palliative population. However, it is not viable as a stand-alone programme due to the high patient to professional ratio, difficulty recruiting and retaining patients, and inconclusive data.

In response to the programme outcomes, we developed a new, shorter group for pain, breathlessness and fatigue replacing the symptom management groups running independently of each other. It incorporates elements of the PMP and responds to patient feedback. We envisage that this will provide a more efficient way of running our symptom groups and that patients will find it beneficial.
Part 2: Progress and outcomes

The Palliative Pain Management Programme (PPMP)

The aim of the PPMP was to improve physical, emotional, functional and social dimensions of health. The programme was aimed at patients with chronic pain (> 3 months) with a palliative diagnosis, in a hospice environment. Patients with life-limiting disease are usually excluded from PMPs that run in mainstream services, leaving a gap in service provision for palliative patients with ongoing pain.

The intervention

Our original intervention was the provision of a biopsychosocial programme delivering pain management principles and strategies at St. Joseph’s Hospice. A 6-week programme of weekly 2.5-hour sessions was delivered by a Physiotherapist and a Clinical Psychologist (Appendix 1a).

Referral criteria enabled referrals from the hospice multi-disciplinary team and the group was publicised across the hospice (Appendix 1b).

Delivering the programme

Three programmes were delivered between November 2016 and April 2017. We identified that the number of referrals to the PPMP was low, with a high rate of attrition. We therefore delayed starting Cohort 4, to increase referrals. The hospice caseload was systematically reviewed but yielded just 3 further potential participants. Whilst Cohort 4 had the largest number of starters, attrition continued to prove challenging.

Figure 1: Referral diagnosis.

This proportion stayed largely the same from referral to completion, i.e. diagnosis did not appear to be a factor in whether or not the participant completed the programme.
Figure 2. Chart indicating flow of patients from referral to completion.

- **35 total referrals**
  - **2 individuals referred twice**

- **Group sessions (Nov 16 - July 2017)**
  - **31 referrals**
    - **Completed initial assessment**
      - **26 patients**
    - **Unable to assess**
      - **5 patients**
        - 2 declined, 2 unwell, 1 unable to contact
    - **Started group**
      - **23 patients**
        - Start data unavailable for 2 patients as did not attend 2nd session
    - **Attended 2nd session**
      - **16 patients**
    - **Completed programme**
      - **11 patients**

- **Individual sessions (ran from August-September 2017)**
  - **4 referrals**
    - Including 1 patient who had declined to complete group intervention
  - **Declined**
    - **1 patient**
  - **Completed programme**
    - **3 patients**
  - **Did not go on to complete**
    - **5 patients**
      - 4 unwell, 1 declined
Following delivery of 4 group cohorts, we trialled an individual programme delivery. We adapted the programme schedule to include 4 x 75 minute sessions to each individual, delivered by one clinician.

**Outcome measures and Data Collection**

A course booklet was completed by patients during or prior to the first and final sessions. This included the following outcome measures:

- **Brief Pain Inventory** - a measure of the intensity and interference of pain
- **Hospital Acquired Depression and Anxiety Scale (HADS)**
- **EQ-5D-5L** – a health related quality of life measure
- **Pain Self-Efficacy Questionnaire** - confidence in ability to perform tasks or confidence in coping with pain
- **Goal Attainment Scaling** – a patient identifies a goal using SMART principles (Specific, Measureable, Appropriate, Realistic, Timely) that they work to achieve with the scaling a method of scoring the extent to which patient’s goals are achieved
Analysis of data - analysed by our project partners at the Cicley Saunders Institute, King's College London (full report at Appendix 1c).

Key learning

1. Quantitative data

As indicated in the analysis of data report (Appendix 1c) there was no change in health outcomes. Therefore, we cannot conclude that the PPMP achieved its aims in improving biological, psychological and social health. The project was limited by the small number of participants completing the course (n=14).

2. Goal achievement

GAS T-Scores changed favourably and significantly indicating the group has motivated people to achieve something they were not doing at the start of the group.

“I will do the morning school run for both my children by the end of the course.” Alex, patient

Alex joined the course during an emergency in-patient symptom control admission. This goal was identified as being ambitious but Alex still used the skills covered in the course to partially achieve this goal, and later reflected that she had set herself a goal that was too difficult at that time. Alex has gone on to require less input from the palliative care team.
3. Qualitative data

Those patients who completed the PPMP were overwhelmingly positive about the programme. Although the health outcome measures did not show improvements, we felt the dedication that completing patients showed to attending, despite significant symptom burden, indicated that they were benefitting in a way that had not been measured by the selected outcomes. Patients found the benefit in being part of a group and being in a safe space to share their experience and journey.

"I will be able to wash under my arms independently" Frank, patient.

Frank was being assisted by his wife, but keen to be independent with as many tasks as he could. The movement and education aspect of the course particularly helped him achieve his goal.

"Although it doesn’t ease your pain, it has helped give me lots of ideas to manage my pain." Pat, patient

"It couldn’t be more helpful and interesting." Clare, patient

"The pacing activities helped. I can remember what to do. I’m still on the same (pain) medication – this hasn’t had to increase which feels like a good thing" Mandy, patient

"I would like to see that programme opening up to many more people" Julia, patient
We also received constructive feedback, which we used to improve the experience:

- a bigger group
- including more exercise
- using techniques other than mindfulness

**Impact around the hospice**

The project developed a good reputation and our colleagues have been very impressed with the programme and how it can complement their own expertise.

> “…this service has been so useful with the care of some of our most complex patients.” Dr Samantha Edward, Consultant in Palliative Medicine & Medical Lead

**Analysis**

The patients completing the PPMP had a deteriorating, progressive illness. While we found no significant improvements in health outcomes, there was no negative trend, indicating the intervention was safe. It was never the intent of the programme to reduce pain and many participants achieved their meaningful goals.

We have reflected on why we had less success in changing the health outcomes and have identified the following points:

1. **Patient heterogeneity.** Identified in their initial measurements and their own disease trajectory. It was difficult to identify a positive change when analysing the data as a whole.

2. **Disease trajectory.** 16% of patients who started the PPMP had died within 2 months of starting the programme; others were too unwell start the programme. It may be harder to show the benefit of a self-management intervention in late stage disease.

3. **Patient complexity.** Of the 14 patients who completed the intervention, at least 7 were very complex, requiring multiple interventions across the Multi-Disciplinary Team (MDT) during outpatient and inpatient episodes, for example:
   - Individual psychological intervention
   - Specialist Pain Consultant
Therefore, the PPMP alone may not have added new knowledge or strategies, or the patient may not have been at the right stage of change at the time of doing the course to implement changes.

4. **Stability.** Patients with pain appeared more unstable than those with breathlessness and/or fatigue and were less able to attend a 6-week programme.

5. **New hospice referrals.** Patients newly referred to the hospice with pain seemed more unstable, potentially reflecting a change in the hospice patient population.

Most importantly, our findings were limited by small participant numbers. With greater numbers an effect may have been seen, particularly in the psychological measures as these showed most positive change.
Part 3: Cost impact

St Joseph’s Hospice provides specialist palliative care, end of life care and respite care for people with progressive and life-limiting illness, and their families and carers. Our services are free to the people who need them. Over 50% of hospice costs are met by local NHS commissioners. The rest of the funding comes from charitable legacies, donations and other fundraising.

We did not intend to carry out a formal economic analysis as part of this project. Costs were predominantly associated with staff costs. When considering the delivery of the programme, the high professional to patient ratio suggests that the PPMP is not cost effective in its original form.

The budgeted costs of the programme were based on our knowledge of other symptom management programmes run by the Therapies Services Team which we used as a model for set up and delivery of the programme. However, the numbers recruited were smaller than we had anticipated.

The implementation phase of the project was used to develop the programme content, recruit staff and deliver the first cohort. We were fortunate that the Physiotherapist who had originally devised the programme was seconded back to the hospice from the Cicely Saunders Institute for this phase. Recruitment of the Clinical Psychologist took three months, which is typical for this level of post in healthcare. The delivery team were in place for January 2017.
Part 4: Learning from your project

The patient cohort

The PPMP operational framework was modelled on our Breathlessness self-management programme. We have learnt that patients with pain are generally more unstable than those who are breathless, impacting on their ability to participate in a group. Potential participants were more difficult to find and the small numbers of completing participants limited the project.

The programme challenged patients to take a different, more holistic view of their pain. We learnt that participants were often open minded when trying something new or thinking differently.

We discovered that pain and fatigue often occur together; patients could lose energy during the sessions so we incorporated more movement to break up the discussions.

Picture 1. Course facilitator and patient

Figure 4. Attendance of patients going on to complete the course. The majority of patients attended all sessions.
**The outcomes of the PPMP**

The outcome measures did not show positive change, aside from goal achievement, meaning our group did not fulfil its aim to improve the biopsychosocial dimensions of health. However, in a palliative population with deteriorating conditions we did not expect participants to experience a reduction in pain, rather that the person’s ability to manage their pain would improve with secondary benefits in various health domains. We are unable to conclude that there were positive effects on health outcomes and were limited by small numbers for analysis.

**PMP Steering Group**

We were supported by a regular Steering Group comprising of project lead, course facilitators, medical, nursing and complementary therapy colleagues, researchers and a patient representative. Group members’ experience in service delivery was beneficial, in both the setup and adaptation of the project. We learnt that innovating new services requires flexibility, determination and adaptation. We found it was invaluable having people from multiple teams and disciplines in the steering group in order to keep the momentum of the project going and fresh in the minds of our colleagues. We reflected that it can take time and energy to establish new services.

We learnt from having researchers from Kings College London to analyse the data robustly and independently; this enabled us to discuss and understand what the data meant more objectively.

**The Course Facilitators and Project Lead**

The facilitators’ skills and growing experience allowed us to gain the trust of the patients and deliver a worthwhile group.

Supervision for the facilitators with a Clinical Psychologist was very helpful. We learnt that containing a high level of emotion whilst trying to deliver a structured, educational course was difficult. We discovered that different people want different things from groups, which can complicate group dynamics, but this also informs project development.

The Project Lead was supportive in enabling changes to project delivery and the Springfield Consultant helped us accept that unexpected challenges are a part of innovation. The workshops enabled us to see that problems have arisen in many innovations, which was reassuring and helped us to continue moving forward.
<table>
<thead>
<tr>
<th>Challenge / Risk</th>
<th>Mitigation Strategies</th>
<th>Effectiveness and learning</th>
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<tbody>
<tr>
<td>Small numbers of patients completing the programme</td>
<td>- Liaison with MDT colleagues in the hospice and attendance at MDT meetings to raise awareness of the programme and increase referrals</td>
<td>- Whilst wider MDT colleagues were very supportive of the programme, the majority of referrals came from within the Therapies Team</td>
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<td></td>
<td>- Dissemination of programme information for patients and staff</td>
<td>- Additional screening identified only 3 potential participants</td>
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<td>- Additional screening of all patients scoring &gt;2 on the IPOS measure</td>
<td>- We did not receive any referrals from the external providers, informing us sustained promotion is required to generate referrals from outside the hospice</td>
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<td>- External liaison with community and secondary care providers</td>
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<td>The significance of patients sharing the challenges of their journey to date and also who they were as individuals beyond their illness</td>
<td>- We adapted the running of the programme allowing space to share an appropriate amount of their experience</td>
<td>- We learnt that allowing space for patients to share seemed to facilitate the group’s ability to remain focused on the course material. We also found that the levels of distress in this patient group were considerable, making this space even more important.</td>
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<td>- We drew on the ground rules set up at the beginning of each cohort to allow us to close down sharing or discussion that became unsafe or inappropriate to the programme</td>
<td>- We discovered smaller groups proved harder to manage with these strategies, a group size of 4 was the minimum workable number. Groups of 2 or 3 were particularly difficult to manage. The individual sessions were the easiest to deliver from our viewpoint – but lost the benefits of efficiency and peer support</td>
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<td></td>
<td>- Signposting or referral to psychology or counselling services were made indicated</td>
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<td><strong>Individual and cultural differences in beliefs about pain</strong></td>
<td>- We did our best to accommodate differences by additional explanation or working with the patient’s own examples</td>
<td>- We felt that the discussion that these situations produced in the group were meaningful for both participants and facilitators</td>
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<td>Elements of the course were predominantly Western or contemporary and difficult for some patients to grasp</td>
<td>- We ensured time for debriefing after each session to allow sharing and validation of our experiences</td>
<td>- We learnt that further consideration should be given to alternative meanings and understandings that our diverse client group may hold</td>
</tr>
<tr>
<td>Impact of group process</td>
<td>- The Project Manager agreed additional supervision from a Clinical Psychologist</td>
<td>- Both debriefing and supervision were vital in allowing us to offload, understand and process our experience.</td>
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<td>As facilitators we were not prepared for the impact that group dynamics, behaviours or transference issues would have on us</td>
<td>Learning to identify the elements that belonged to us as separate from those that were patient generated helped us to process the work</td>
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As the project team worked hard on delivering a quality intervention, it was disappointing that the quantitative results were not more positive and the participant numbers small. We concluded that within our hospice, the PPMP was not a viable, stand-alone group in its current format. We will be able to embed some of the useful content and findings into other groups and develop a more effective intervention.

11 referred patients did not want to attend a group, showing us that a group intervention is not always appropriate. Furthermore, a high proportion of patients who wanted to attend were unable due to disease progression. Identifying that few hospice patients remain stable enough from referral to completion informed our shortening of the duration of the PPMP and future programmes in our hospice.
Our key learning points are:

- the PPMP is not sustainable at our hospice in its current format due to
  - high attrition, secondary to disease progression and fluctuation, frequently observed in patients in the last year of their lives
  - low numbers of suitable patients on hospice caseload
- patients who wanted to and were able to attend found the content and experience useful

We hypothesise that:

- a PPMP may be viable earlier on the disease trajectory
- the content is useful to patients with other symptoms, namely breathlessness and fatigue
- the biopsychosocial approach to pain can be incorporated into 1:1 sessions within standard therapy provision with good effect

There is huge value to this learning, and we are taking these points forward for our future service development.
Part 5: Sustainability and spread

Sustainability

The difficulty in recruiting patients and the high attrition rate resulted in a high patient to professional ratio. We feel the PPMP is not a viable intervention in its present form, as a stand-alone programme. However, we identified that the content and psychological approach is applicable to pain and other symptoms commonly found in palliative care patients, namely breathlessness and fatigue. The project has raised the awareness of holistic pain management and the complexity of pain within the Therapies Services Team.

The Therapies Services Team already runs symptom-specific groups for management of breathlessness and for fatigue, with similar problems relating to attrition, although not to the extent seen in the pain programme. Having reviewed the PPMP and using the learning from this project, in collaboration with the Therapies Services Team we will run a pilot group of a new, integrated programme; "I Can Manage My Symptoms" (‘ICan’) which will be:

- shorter, taking place over 4 weeks, to address the attrition rate noted in the PPMP and also fatigue and breathlessness management groups
- adapted, so it is relevant to other symptoms namely breathlessness and fatigue
- planned to run more frequently, so patients can be offered it at a time in their disease trajectory that is suitable for them
- each session planned as a complete treatment, with an educational, exercise and relaxation component, so even if a patient is only able to attend one or two sessions, they would still benefit from experiencing a range of strategies
- larger cohorts, in direct response to patient feedback and facilitator reflection. This will enable a better group experience for the patients and facilitators, and provides a more efficient use of resources

(See Appendix 1d for ‘ICan’ programme content.)

ICan will enable us to transform the PPMP by addressing the patient feedback and acknowledging our learning.

The PPMP psychologist has made a case for continued input from Psychological Therapies within the hospice to assist with delivery of the programme. At present, this service is interested in supporting the group on going, with cost implications for sustainability to be considered after the pilot group.
Following the running of the new integrated self-management group, ‘ICan’, patient feedback and outcomes will be reviewed and plans for staffing beyond the current funding will be made.

Based on our learning, the course should continue to be delivered by experienced specialist palliative care therapists, in order to provide the necessary support and guidance for the patients. We found sessions could be emotionally charged and required careful management to ensure a beneficial group for everyone.

In order to sustain this model we may need to identify further funding to cover any additional professionals from outside the Therapy Services Team, for example input from Psychological Therapies, as well as additional costs such as catering and transport. Assuming a successful analysis of the pilot ‘ICan’ group, we will work with the Therapies Services Managers to identify how the re-designed programme is embedded into Therapies Services provision.

Upcoming milestones:

<table>
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<tr>
<th>October – November 2017</th>
<th>Pilot of ICan programme</th>
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<tr>
<td>November 2017</td>
<td>Evaluation of pilot ‘ICan’ programme</td>
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<tr>
<td>December 2017</td>
<td>Marketing and relaunch of self-management groups in the new format ‘ICan’.</td>
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<tr>
<td>January 2018</td>
<td>Next cohort of ‘ICan’ to start</td>
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Spread

Having identified some of the challenges and benefits involved in running a palliative pain management group in a hospice environment, we are keen to share our findings. Our plans include dissemination to:

- Hospice UK conference 2018
- Association of Chartered Physiotherapists in Oncology and Palliative Care (ACPOPC) for opportunities to present learning, for example in upcoming study days
- eHospice UK
- Kings College London for further opportunities and to consider working towards publication
Acknowledgements

The project team would like to express their deep appreciation and thanks to the following people for their considerable assistance during the course of the project and service evaluation:
Lucy Fettes, Cicely Saunders Institute, Kings College London
Matthew Maddocks, Cicely Saunders Institute, Kings College London
Richard Edgeworth, Springfield Consultancy
All members of the PPMP steering group, St Joseph’s Hospice
The Health Foundation
Our patient participants
Appendix 1: Resources and appendices

Appendix 1a. The 6-week group programme schedule

The Living *through* Pain Programme – 6wk

*Co-tutors:* Physiotherapist- Gemma Wardle, Clinical Psychologist- Karen Piper

*Dates:* Fridays 10.30am- 1pm at St Joseph’s Hospice

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<tr>
<th>Session 1</th>
<th>Session 2</th>
<th>Session 3</th>
<th>Session 4</th>
<th>Session 5</th>
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<tr>
<td>Understanding pain and its impact</td>
<td>Self-monitoring and goal setting</td>
<td>Coping with emotions and physical symptoms</td>
<td>Pain theory and moving with pain</td>
<td>Managing life situations and problem solving</td>
<td>Maintaining progress and managing changes in pain</td>
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<tr>
<td>Introductions and ground rules of the course</td>
<td>Review of the week and homework tasks</td>
<td>Review of the week and homework tasks</td>
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<td>Discussion on the nature and impact of chronic pain</td>
<td>Introduction to pacing, the boom bust cycle, baselines and relaxation</td>
<td>Discussion surrounding emotions, thought and thought management, communicating pain, and managing flare-ups</td>
<td>Discussion around beliefs and fears surrounding pain, the Pain-Gate theory and possible coping strategies, including use of medication and it’s side effects</td>
<td>Introduction to problem-solving method: Participants discuss how to manage particular activities they find difficult</td>
<td>Discussion and set plans for coping with pain and when to seek help</td>
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<tr>
<td>Completion of Outcome assessment booklet</td>
<td>Reflection exercise on the quality of life</td>
<td>Participants discuss other symptoms experienced alongside pain i.e. fatigue, sleep problems, and other side effects</td>
<td>Participants discuss use of exercise and moving with pain, with reference to the chronic pain cycle</td>
<td>Practice stretches and build up functional exercises as appropriate for each individual incorporating coping strategies as required</td>
<td>Recap / discussion surrounding what participants have learnt from the course</td>
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<tr>
<td>Participants explore self-management ideas / discuss expectations of programme</td>
<td>Goal setting principles and practice</td>
<td>Introduction to mindfulness, relaxation and distraction</td>
<td>Introduction of stretches and functional exercises</td>
<td>Managing flare-ups</td>
<td>What next? – How to maintain progress / signposting to other services</td>
</tr>
<tr>
<td>Balancing life with pain, pacing principles, activity diary and enjoyment goals</td>
<td>Set Homework Task / weekly goal</td>
<td>Set Homework Task / weekly goal</td>
<td>Set Homework Task / weekly goal</td>
<td>Set Homework Task / weekly goal</td>
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<td>Mindfulness Exercise</td>
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Participants discuss use of exercise and moving with pain, with reference to the chronic pain cycle

Introduction of stretches and functional exercises

Set Homework Task / weekly goal

Review of set goals/outcomes

Practice stretches and functional exercises

What next? – How to maintain progress / signposting to other services
Appendix 1b. Initial referral process.

The Living *through* Pain Programme (LTP) Referral Process

LTP Referral Criteria
- Patients under the care of St Joseph’s Hospice
- Patient’s must have advanced progressive disease
- Persistent pain/s for > 3 months or such patients with controlled pain wishing to reduce medication and related side-effects or improve function
- Pain relating to advanced progressive disease or related treatment or indirectly related, (i.e. longstanding musculoskeletal pain or arthritis which may be exacerbated by their condition)
- Phase of illness: stable/unstable
- Karnofsky Performance Scale rating of 50-100%
- Medically optimised – known to CNS and discussed at MDT
- Good understanding of the English language
- Ability to comprehend and participate in course content and homework tasks and evaluation
- Ability to attend an out-patient programme once a week for 6 weeks (transport provided if needed)

Inform referrer/document in notes

Internal Referral to Physiotherapy via Cross Care (patient provided with brief LTP Information leaflet)

Not suitable for LTP

LTP Lead to telephone patient and *triage* for eligibility to LTP and make appointment for initial assessment if appropriate
LTP Lead: Physiotherapist - Lucy Fettes

Specialist LTP Ax
Eligibility for PMP: T/ Therapies/Operational frameworks/LTP
- Persistent pain is main disabling symptom
- Comply with referral criteria as above
- Functional limitation due to persistent pain
- Identifiable functional goal
- Motivated to engage with a group self-management programme addressing change in behaviours
Complete LTP Assessment Sheet (essential info)

Suitable to attend

Invite to LTP Programme
Admin process with Invitation letter + programme content + dates
If from waiting list referring physio to remind patient and re-check suitability
Appendix 1c. Data analysis report from Kings College London.

Demographics
Across the cohorts, 24 patients had completed the pre-intervention measures, 2 further patients started but we did not have their initial data booklets as they took them home to complete and then did not return to the group. The group, based on the data available, (17 female (71%)) had a mean (SD) age of 59 (13) years and a median (IQR) Karnofsky Performance Status was 70 (60-70) indicating a reasonable level of functional independence. This is corroborated by not one patient having a care package in place, despite 9 (38%) living alone.

Twenty one (88%) had a primary cancer diagnosis and two (8%) a primary neurological diagnosis, and one (4%) a cardiovascular disease. Most patients had 1-2 comorbidities and the mean (SD) Chairson score was 8.2 (4.1). The majority of patients attending (n=21, 88%) were in the stable phase of disease and few were in an unstable phase (n=3, 12%).

Health outcomes

Pain intensity and interference

The Pain Research Group of the WHO Collaborating Centre for Symptom Evaluation in Cancer Care developed the Brief Pain Inventory (BPI) initially as a pain assessment tool for use in people with cancer. The BPI measures both the intensity of pain (sensory dimension) and interference of pain in the patient's life (reactive dimension). It has demonstrated reliability and validity across cultures and languages, is being adopted in many countries for clinical pain assessment, epidemiological studies, and in studies of the effectiveness of pain treatment.

The BPI short form consists of nine items. The first, optional, item is a screening question about the respondent's pain on the day. The questionnaire is then composed of pain drawing diagrams, four items about pain intensity (worst pain, least pain, average pain, pain right now), two items on pain relief treatment or medication, and one item on pain interference, with seven sub-items (general activity, mood, walking ability, normal walk, relations with other people, sleep, and enjoyment of life). The BPI gives two main scores: a pain severity score and a pain interference score. The pain severity score is calculated from the four items about pain intensity. Each item is rated from 0, no pain, to 10, pain as bad as you can imagine, and contributes with the same weight to the final score. The pain interference score corresponds to the item on pain interference. The seven sub-items are rated from 0, does not interfere, to 10, completely interferes, and contributes with the same weight to the final score. Both scores are average with a possible 0-10 with a higher score indicating worse pain intensity or more pain interference.

Based on the available data there was no observable effect on pain intensity and or pain interference as measured by the BPI. The interpretation is hampered by only having 14 patients completing the PMP. A non-parametric Wilcoxon signed rank test could not reject the null hypothesis that the PMP has no effect on pain intensity (p=0.30) and or pain interference (p=0.18) (see figure 7).

Pain self-efficacy
Self-efficacy beliefs assess confidence in ability to perform specific tasks or to confidence in performing more generalised constructs like coping with pain. In this context, self-efficacy beliefs for people experiencing chronic pain might be expected to incorporate not just the expectation that a person could perform a particular behaviour or task, but also their confidence in being able to do it despite their pain. This aspect has been assessed using the Pain Self-Efficacy Questionnaire (PSEQ). The PSEQ has been validated with confirmatory analysis in a large cohort of heterogeneous chronic pain patients attending a pain management clinic for chronic low back pain.

The PSEQ is a 10 item self-report inventory to assess a chronic pain patient’s belief that he/she can perform various activities or functions despite pain. Items include such statements as: “I can do most of the household chores (e.g., tidying-up, washing dishes, etc.) despite the pain” and “I can gradually increase my activity level, despite the pain”. Subjects are asked to rate how confident they are that they can do each of the ten activities or functions at present by selecting a number on a 7-point scale, where 0 equals ‘not at all confident’ and 6 equals ‘completely confident’. A score for the PSEQ is calculated by summing the scores for each of the ten items, yielding a maximum possible score of 60. A higher score indicates better self-efficacy.

Based on the available data there was no observable effect on pain self-efficacy as measured by the PSEQ. The interpretation is hampered by only having 14 patients completing the PMP. A non-parametric Wilcoxon signed rank test could not reject the null hypothesis that the PMP has no effect on pain self-efficacy (p=0.34) (see figure 7).

Anxiety and depression
- Stern AF. The Hospital Anxiety and Depression Scale. Occupational Medicine 2014;64:393–394

The Hospital Anxiety and Depression Scale (HADS) was devised 30 years ago by Zigmond and Snaith. The HADS questionnaire has been validated in many languages, countries and settings including general practice and community settings [5–7]. It is useful for initial diagnosis and to track progression (or resolution) of psychological symptoms. It is one of the National Institute for Health and Care Excellence (NICE) recommended tools for diagnosis of depression and anxiety. The questionnaire has 7 items that relate to anxiety, e.g. I feel tense or wound up, or I feel restless and have to be on the move, and 7 items that relate to depression, e.g. I feel as if I am slowed down, or, I look forward with enjoyment to things. Each item on the questionnaire is scored from 0-3 and this means that a person can score between 0 and 21 for either anxiety or depression. A higher score indicates a worse state of anxiety or depression. Cut-off scores are available for quantification, for example a score of 8 or more for anxiety has a specificity of 0.78 and a sensitivity of 0.9, and for depression a specificity of 0.79 and a sensitivity of 0.83.

Based on the available data there was no detectable effect on pain self-efficacy as measured by the PSEQ. The interpretation is hampered by the small sample size, which cannot be confirmed to be at random, precluding any imputation methods. A non-parametric Wilcoxon signed rank test could not reject the null hypothesis that the PMP has no effect on state anxiety (p=0.10) or depression (p=0.08) (see figure 7).

Health related quality of life
- [https://euroqol.org/](https://euroqol.org/)

The 5-level EQ-5D version (EQ-5D-5L) was introduced by the EuroQol Group in 2009 to improve the instrument’s sensitivity and to reduce ceiling effects, as compared to the EQ-5D-3L. The EQ-5D-5L essentially consists of 2 pages: the EQ-5D descriptive system and the EQ visual analogue scale (EQ VAS). The descriptive system comprises five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression.
Each dimension has 5 levels: no problems, slight problems, moderate problems, severe problems and extreme problems. The patient is asked to indicate their health state by ticking the box next to the most appropriate statement in each of the five dimensions. The EQ VAS records the patient’s self-rated health on a vertical visual analogue scale, where the endpoints are labelled ‘The best health you can imagine’ and ‘The worst health you can imagine’. The VAS can be used as a quantitative measure of health outcome that reflect the patient’s own judgement. It can be scored 0-100 with a higher score indicating a better health state.

Based on the available data there was no effect on health related quality of life as measured by the EQ-5D VAS. The EQ-5D utility scores (not presented) demonstrate a very similar pattern. A non-parametric Wilcoxon signed rank test could not reject the null hypothesis that the PMP has no effect on quality of life (p=0.88) (see figure 7).
Figure 7: Health outcomes assessed before and after the pain management programme.
Goal setting and attainment


Goal setting was applied using the 'GAS-light' method, developed by Turner-Stokes, which is based on the original GAS methods but designed to be practical for use in the clinical setting. GAS-light resolves some historic criticisms of GAS such as the time consuming nature of goal difficulty rating and numerical scoring. Each patient sets up to three goals with their care provider(s), and family where relevant, highlighting the most important goal at the time. Goals must be SMART (specific, measurable, achievable, realistic and timed) and thus incorporate a validated outcome tool. A goal statement is recorded to describe the intended outcome for each goal, e.g. “to improve sit-to-stand performance from 16 to 12 seconds on the 5-sit-to-stand test over 4 weeks”.

Patient’s goals on entering the PMP are shown below. Of note, only one goal related to the participant’s pain; the majority related to the performance of tasks and activities and participatory functions, e.g. travelling to bingo, or the coffee shop. Over half related to community, social and civic life, and around one-third related to mobility or Interpersonal interactions and relationships.

♀ PMP Goals

<table>
<thead>
<tr>
<th>Goal</th>
<th>ICF code</th>
<th>Code description</th>
<th>ICF category</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>d920 b280</td>
<td>Recreation and leisure Pain</td>
<td>P</td>
</tr>
<tr>
<td>2</td>
<td>d950 d465</td>
<td>Any other activity or participation Moving around with equipment</td>
<td>P</td>
</tr>
<tr>
<td>3</td>
<td>b152 d210 d450 d920</td>
<td>Emotional function Undertaking a simple task walking Recreation and leisure</td>
<td>P</td>
</tr>
<tr>
<td>4</td>
<td>d465 d750 d920</td>
<td>Moving around with equipment Informal social relationships Recreation and leisure</td>
<td>P</td>
</tr>
<tr>
<td>5</td>
<td>d760</td>
<td>Family relationships</td>
<td>P</td>
</tr>
<tr>
<td>6</td>
<td>d920</td>
<td>Recreation and leisure</td>
<td>A</td>
</tr>
<tr>
<td>7</td>
<td>d510</td>
<td>Washing oneself</td>
<td>A</td>
</tr>
<tr>
<td>8</td>
<td>b134</td>
<td>sleep</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>b134</td>
<td>sleep</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>d450</td>
<td>walking</td>
<td>A</td>
</tr>
</tbody>
</table>
11. I will do some stretches every morning in the garden.

12. To arrange and go on a date night with partner every month.

13. To arrange a trip to the theatre himself to increase quality time with partner.

14. To practice 5 minutes of mindfulness on school days within 2 weeks.

❖ Frequency of ICF Codes among all 14 goals

<table>
<thead>
<tr>
<th>Rank</th>
<th>ICF Group code</th>
<th>Description</th>
<th>Frequency (n (%) )</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>d9</td>
<td>Community, social and civic life</td>
<td>8 (57)</td>
</tr>
<tr>
<td>2</td>
<td>d7</td>
<td>Interpersonal interactions and relationships</td>
<td>4 (29)</td>
</tr>
<tr>
<td>3</td>
<td>d4</td>
<td>Mobility</td>
<td>4 (29)</td>
</tr>
<tr>
<td>4</td>
<td>b1</td>
<td>Mental Functions</td>
<td>3 (21)</td>
</tr>
<tr>
<td>5</td>
<td>d2</td>
<td>General tasks and demands</td>
<td>1 (7)</td>
</tr>
<tr>
<td>6</td>
<td>d5</td>
<td>Self-care</td>
<td>1 (7)</td>
</tr>
<tr>
<td>7</td>
<td>b2</td>
<td>Sensory Functions and Pain</td>
<td>1 (7)</td>
</tr>
</tbody>
</table>

At treatment follow-up, which is defined by the goal timeframe and should vary case-by-case but was predominantly at the end of the planned PMP, attainment for each goal was recorded based on a review of the statement. GAS-light uses a 6-point verbal rating scale to capture goal attainment, which reflects the way goals are usually recorded in practice. Verbal ratings are converted onto 5-point numerical scales (-2 to +2), depending on their baseline rating. For each patient, a composite T-score (0-100) will be derived from the product of individual goal achievement scores that is normally distributed and can be compared across different goal sets. A higher score indicates better goal attainment. Goal attainment was generally only reported for the patients that completed the PMP. It should be acknowledged that goals set by patients who did not complete the PMP are not featured in the figure below. However, GAS t-scores changed favourable and significantly following the PMP (p=0.003) with on average a 15 point increase from before to after the programme.
Patient Feedback
Patient satisfaction was assessed using items from the Functional Assessment of Chronic Illness Therapy – Patient Satisfaction (FACIT-PS) questionnaire to explore perceptions of clinical explanations, trust, and overall experience. Permission was granted to modify the satisfaction questionnaire to ensure that selected questions pertained to the rehabilitation service and staff.

Responses were scored on a 0-3 scale with 0 indicating poor, 1 indicating fair, 2 indicating good and 3 indicating excellent. Patient feedback was only received by those patients who completed the PMP (n=14). Overall, their experience was excellent. Items rated as good on average related to the length and location of the PMP (question 9 and 10 respectively).

❖ Questions

<table>
<thead>
<tr>
<th>Feedback Question</th>
<th>Median (IQR)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Did your course tutors give explanations that you could understand?</td>
<td>3 (3,3)</td>
</tr>
<tr>
<td>2. Did you have the opportunity to ask questions?</td>
<td>3 (3,3)</td>
</tr>
<tr>
<td>3. Did you get to say the things that were important to you?</td>
<td>3 (2,3)</td>
</tr>
<tr>
<td>4. Did your course tutors seem to understand what was important to you?</td>
<td>3 (2,3)</td>
</tr>
<tr>
<td>5. Did you have confidence in the course tutors?</td>
<td>3 (3,3)</td>
</tr>
<tr>
<td>6. Would you recommend the 'Living through Pain Programme' to others?</td>
<td>3 (3,3)</td>
</tr>
<tr>
<td>7. How do you rate the overall content of the programme?</td>
<td>3 (2,3)</td>
</tr>
<tr>
<td>8. How do you rate the delivery of the programme?</td>
<td>3 (2,3)</td>
</tr>
<tr>
<td>9. How do you rate the length of the programme (3hrs)?</td>
<td>2 (2,3)</td>
</tr>
<tr>
<td>10. How do you rate the location of the programme?</td>
<td>2 (2,3)</td>
</tr>
<tr>
<td>11. How helpful was Session 1: Understanding pain and its impact?</td>
<td>3 (3,3)</td>
</tr>
<tr>
<td>12. How helpful was Session 2: Self-monitoring and goal setting?</td>
<td>3 (3,3)</td>
</tr>
<tr>
<td>13. How helpful was Session 3: Coping with emotions and physical symptoms?</td>
<td>3 (2,3)</td>
</tr>
<tr>
<td>14. How helpful was Session 4: Pain theory and moving with pain?</td>
<td>3 (2,3)</td>
</tr>
<tr>
<td>15. How helpful was Session 5: Managing life situations and problem solving?</td>
<td>3 (3,3)</td>
</tr>
<tr>
<td>16. How helpful was Session 6: Maintaining progress and managing changes in pain?</td>
<td>3 (3,3)</td>
</tr>
</tbody>
</table>
Patients were also asked for their free-text comments relating to suggested changes for
the PMP content, structure and delivery, and any other feedback they wished to offer.
*Verbatim* statements are shown below, grouped according to the nature of the feedback
(positive, neutral, critical):

**Positive**
- No, nothing, everything was fine. No problems with how it was run and able to ask
  questions.
- No changes
- I felt that the physiotherapist led and the psychologist kept a "watchful" silence -
  though it didn't feel very watchful.
- Though I didn't achieve my goals I felt I had!!! As it made me realise that I was
  unrealistic
- No changes
- I would like to see the programme opening up to many more people.
- It couldn't be more helpful and interesting
- Very good programme.
- Due to my condition, I did fall asleep but still understood the lessons being
  explained to me. Good tutoring very patient and helpful.
- Although is not completely easing your pain, but this has given me help to manage
  my pain. Its nice to talk to the patients.

**Neutral**
- Well done for ploughing on with just 2 of us, as I would have been disappointed but
  you didn't seem to be

**Critical**
1. group size:
   - Would have been nice to have a larger group.
   - To expand on the group size, use of the garden room and first floor overlooking the
     garden.
   - Although "lovely" it felt a lot of resources were used for two patients.
2. Longer discussion
   - Allow a "contained" level of emotions within the group - let people have their "say"
   - Ensure that everyone gets a say as much as possible.
   - Having longer to discuss pain issues within the group personal to the group
     member, to lessen the feeling of "being shut down."
   - In the first session (the course tutors) asking more than 1 question to be shared
     with the group after telling your partner about yourself.
   - More interaction between us and them
3. Other suggestions
   - Try and find a different ice-breaker? Look up on website, lots of ideas
   - Give a better option for those who don't want to do mindfulness.
   - Make each session more desirable by including short, fun activities to keep
     attendance by participants more likely
   - Get specific health questions also have a nurse to discuss dressing and other care
     management issues.
   - Before we start the programme it would be nice to have a little exercise or workout
     (about ten mins), and also near to the end with mindfulness too. In every session.
   - Different refreshments: -decaffeinated coffee, -juice, - ?chocolate
• Time should be kept to as often gets taken by patients
• I'd be careful in who I recommended the Pain Programme to! Needed better seating for us, not comfortable in chairs, but much was made of trying to make us comfortable. In first few weeks group was interrupted by Physios needing equipment from the room! I'm a nurse so knew the theory of pain & moving with pain
• I'd like a 2nd call during the week to find out how we (the course members) are doing through the week. Catering is not great neither.
• This has been a useful course but review how much content is in each session so that each session has a similar amount of intensity/demands.
Appendix 1d. ICan *Manage My Symptoms* – course outline

- Course runs over 4 weeks
- Patient attend 1 x symptom specific session in first week as most appropriate to their symptoms i.e. either the Fatigue, Pain or Breathlessness session
- All patients then attend the 3 further sessions, 1 per week, which contain the material which is relevant to all symptoms

<table>
<thead>
<tr>
<th>ICan Manage Fatigue</th>
<th>What is fatigue and its effects</th>
<th>Exercise for fatigue</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>How fatigue feels to you</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Identifying when you are most or least energised</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ICan Manage Breathlessness</td>
<td>Exercise for breathlessness</td>
<td>Communication and swallowing</td>
</tr>
<tr>
<td></td>
<td>Anatomy of breathlessness</td>
<td>Anxiety relating to breathlessness</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Fan therapy, breathing control</td>
</tr>
<tr>
<td>ICan Manage Pain</td>
<td>The Pain Gate/ Pain Theory / Cycle</td>
<td>The Power of Exercise for Managing Pain</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Medication for Managing Pain</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Using Activities, Thoughts and Beliefs to Manage Pain</td>
</tr>
<tr>
<td>ICan Manage my Symptoms: Session 1</td>
<td>The bio-psycho-social approach and balancing life with symptoms</td>
<td>Managing stress and stressful situations</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Sleep</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mindfulness</td>
</tr>
<tr>
<td>ICan Manage my Symptoms: Session 2</td>
<td>Boom and Bust Cycle and how to avoid it</td>
<td>Pacing and Energy Conservation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Wheel of Life and SMART Goal setting</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Qigong</td>
</tr>
<tr>
<td>ICan Manage my Symptoms: Session 3</td>
<td>Thoughts, Emotions and Communication</td>
<td>Nutrition</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Planning to stay well</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Aromatherapy</td>
</tr>
</tbody>
</table>