

## Introduction

500,000 people of all ages in Northern Ireland live with chronic pain, often lingering on hospital waiting lists. The paucity of pain management support services and the plight of many people living with pain hasn't traditionally received as much attention as other long-term conditions.

Better Days Pain Support Programme is a collaborative cross-sectoral project aimed at improving social and mental health outcomes for people experiencing chronic pain in NI. Partners include the Healthy Living Centre Alliance (community), Public Health Agency (PHA), Health & Social Care Board (HSCB), Queens University Dept of Psychology, doctors and pharmacists. The project began as a successful pilot in 2017 and has since evolved into a region-wide series of programmes facilitating a support and self-management approach to pain using a community development model.

It is an innovative, flexible, 10-week programme involving pharmacists, physiotherapists, complementary therapists and community development workers who facilitate a peer-led approach including increasing patient knowledge of pain, challenging their reliance on medication, encouraging patients to own and overcome their pain, improve their mental health through social inclusion and self-efficacy, facilitate an appropriate gentle exercise regime and involve them in determining elements of the course and nature of the programme.

The HLC Alliance provides effective regional coordination as a key element of the Steering Group, which provides quality assurance, while the Pain Support Facilitators in Healthy Living Centres provide the local approach.

Now in its 4th year, Better Days<sup>1</sup> has been molded into a highly popular programme delivered from more than 20 neighbourhoods across the region throughout the year. Now an award-winning programme (NHS Pharmacy and Medicines PrescQIPP award), it is highly replicable. This evaluation will focus on the programme delivered during Covid-19 lockdown conditions, converted to online and delivered from 40 locations to 309 people in two tranches between September 2020 and March 2021.

The overall goal is to improve quality of life i.e., social, physical and mental health outcomes for people experiencing chronic pain in the region. Our intention in preparing for this series of programmes was that, by the end of the operational year, Beneficiaries would have -

- better understanding of chronic pain and its relationship to physical, mental and social wellbeing
- reduced reliance on pain medication
- better understanding of other strategies for managing pain (movement, diet, sleep)
- reduced social isolation
- improved self-efficacy
- better pain self-management

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<sup>1</sup> The programme was formally titled *Better Days Pain Support Programme* during 2021 after a period of consultation with programme beneficiaries and facilitators

The Better Days programme consists of the following topics over an 8–10-week online period

Week	Topic / facilitation	Key facilitator information
1	Introduction Programme planning with participants Introduction to your HLC and other programmes on offer	Led by HLC facilitator Outline programme Ask for participant suggestions Get to know your group Fill in week 1 monitoring
2	Understanding Pain and Types of Pain Intro to Pain self-management Chi Me session	Led by HLC facilitator Slides can be used from Pamela/Christine's presentation
3	Session on Pain toolkit Visit from local pharmacist	Engage local pharmacist for medication checks and 1-1 sessions with participants HLC facilitator to lead session on pain toolkit
4	Session on Pain toolkit Chi Me session	HLC facilitator to lead
5	Sleep and Pain Chi Me session	HLC facilitator to lead
6	Nutrition and Pain	HLC facilitator to lead – Presentation will be sent out for guidance
7	Introduction to Take 5 Group chosen movement session or chi me	HLC to lead take 5 info
8	Take 5 recap or group chosen topic or activity	HLC to lead on take 5 info
9	Group chosen topic or activity	
10	Visit from Pain physio or local MDT physio if possible – more information on movement and pain	Contact Physio in your area, or a fitness instructor with Exercise referral experience in pain
11	Visit from Local pharmacist Chi me or group chosen movement	Key info for participants
12	Final session Key info on HLC programmes and further programmes Discuss how group should proceed into support group	HLC to lead

### Quality Assurance

Better Days Pain Support Programme has been designed to assist those living with long-term pain to live better with their pain by transforming their experience as passive sufferers to proactive practitioners of self-management.

The HLCA Pain Steering Group, with its blend of pain specialists, health professionals, community leadership and academics, is the ideal vehicle for the programme. The Steering

Group meets circa eight times per year to plan training, aid continuous improvement, update and agree the monitoring approach and assist the Pain Support Facilitators in overcoming logistical challenges.

Members of the HLCA Pain Support Steering Group are **Tony Doherty** – *HLC Alliance*, **Natasha Brennan** – *Lorag HLC*, **Dr Christine McMaster** – *Public Health Agency*, **Dr Pamela Bell** – *Chair NI Pain Forum*, **Prof Kevin Vowles** – *Queens Psychology*, **Dr Patrick McAleavey** – *Public Health Agency*, **Anne-Marie Groom** – *Pharmacy Advisor HSCB* and **Deborah McCord** – *Commissioning HSCB*, and GPs Dr Ian Ryans and Dr Peter Ryan.

The programme is now award-winning, having scooped the 2020 NHS PrescQIPP Award for Delivering Across Integrated Care Settings and also took the Overall Silver Award on the day of the award ceremony.

### **The Role of the Pain Support Facilitators**

Before the pandemic the Alliance had trained several dozen Health Development Workers in HLCs as Pain Support Facilitators, whose role was to deliver the programme in a group setting in a Healthy Living Centre. Very few had been previously trained to deliver health programmes online. Therefore, the objective of delivering programmes during a pandemic had to be realised by online training for Pain Support Facilitators on chronic pain, sleep and diet, Chi Me Gentle Exercise, outcome monitoring, as well as how to deliver online course safely during the pandemic.

Quality assurance, agreed programme modules and referral pathways, outcome evaluation, and support for staff during the pandemic were provided by the cross-sectoral Steering Group.

The training provided key support as facilitators moved into the unknown of delivering to vulnerable participants online. We supported some 46 facilitators through monthly peer support meetings over zoom with an average attendance of 30 facilitators per meeting. This allowed the sharing of issues, good practice and contacts with each other as well as informal support training from Alliance and the Pain Support Steering Group.

### **Essential Criteria for each Chronic Pain Support Group**

The framework for the chronic pain support groups was devised in consultation with chronic pain experts, patients, medics and HLC staff and managers.

- Target participants: 8 people via zoom online sessions
- Target delivery – 1 session per week for a minimum of 8 weeks and maximum of 12 weeks
- Each group must have an anchor facilitator as point of contact for the full programme in each centre
- This facilitator must have qualifications in Personal Development and Mental health First Aid or equivalent and also experience in delivery of these aspects.

### Better Days Pain support programme outputs

Output	Total No
HLA Staff trained to deliver chronic pain support programmes (2 sessions)	46
HLCA Staff trained in Chi Me, a softer version of Tai Chi more suited to people living with chronic pain	19
Number of programmes delivered	45
Total number of Hours Chronic pain support programmes delivered	440
Total number of participants / clients	309
Total number of attendances	2300
Number of Pain Steering Group meetings	5
Number of Pain facilitators support meetings	9
Number of Pain facilitators training sessions	3

### Programme Demographic

#### Patients Long-term Conditions

Of participants over 267 listed their conditions with a large percentage having more than one condition and mental health issues attached to more than 47% of referrals.

#### *Range of Chronic Pain reported on Registration*

Arthritis	ME / Chronic fatigue	Migraines
Rheumatoid Arthritis	Back or spinal injuries	Slipped discs
Knee Pain	Back pain	COPD
Fibromyalgia	Nerve damage / pain	Osteoarthritis
Gout	Fibromyalgia	Joint pain and inflammation – Hips, knees, wrists, elbows

Interestingly 58.9% of all those referred had a form of arthritis and the most common areas of pain reported were Hips, knees and wrists. The second most referred condition at 23.3% of all referrals was fibromyalgia including 13.7% of referrals having fibromyalgia as well as naming a particular joint pain area such as back, hip and knee. This in many cases was paired with other issues such as nerve pain, thyroid problems or mental health concerns such as depression or anxiety. The referrals for nerve-based pain increased dramatically in 2020/21 from around 5% in 2019/20 to 14.5% during this year.

### **Delivery during Lockdown**

The target population for the programmes were adults living with chronic pain and, more than likely, living in an area of social deprivation. Such populations are likely to have a higher-than-average range of co-morbidities and pre-existing health conditions; low to moderate mental health issues i.e., anxiety, mild depression, loneliness, social exclusion, low health literacy, a risk of, or real, dependency on pain medication both prescribed and bought. There is higher unemployment, and low social mobility. Many are preoccupied with their pain condition and not actively aware of or using condition-specific self-care techniques, and do not have a clear sense of control over their own health.

During the lockdown we targeted 309 people from the above demographic residing in 20 locations, both urban and rural. The primary method used to reach them was social media for self-referral, while the secondary methods were from primary care and social prescribing.

We delivered 40 programmes in two tranches from September 2020 to March 2021. Minimum participants allowed per programme reduced from 12 to 8/10 as a result of the pandemic.

### **Outcome/Impact**

The following were assessed at weeks 1 and 10 of the course and at 3 months post course:

- Pain was assessed on a 3-point scale - no pain, moderate pain or discomfort, extreme pain
- Online medication questionnaire recorded medication use.
- Online questionnaire with free text section recorded
  - engagement in self-management techniques (e.g., stretching, movement, relaxation, complementary therapies)
  - self-assessment of social engagement and benefits of the course
- EQ-5D and COMM-9 were measured to determine generic health status and health behaviour change respectively.

### **Outcomes of the programme**

*Those experiencing 'Extreme Pain or Discomfort' halved between weeks 1-10, while those with moderate pain reduced from 62 to 42.*

### **Reliance on pain medication**

- *Those relying heaviest on medication, reduced in number from 32 to 7 between weeks 1-10 (5 on 5pt scale), those on point 4 on the scale reduced from 65 to 42, while there was a corresponding increase on point 3 of the scale from 14 to 38.*
- *There was a dramatic drop in the number preoccupied with their opioid medication. Those who 'thought often and very often' about their medication were reduced from 45 to 15.*
- *In week 1, 80% of all participants either rested or did nothing to help their pain; by week 10 'rest' was reduced to 28% while those who 'did nothing' registered at 0%.*

### **Using other strategies for managing pain (movement, diet, sleep)**

- *In week 1 those using Stretching, Alternative Therapies, Relaxation Techniques, Movement/Exercise amounted to 20%. By week 10 this percentage increased to 75%.*

### **Mental health**

- *The number reporting moderate to extreme anxiety/depression reduced from 153(week 1) to 66(week 10)*

We can conclude that Healthy Living Centres facilitated 40 pain support programmes out of a planned 46 with an average week 1 attendance of 7 participants. While there was a lower number of programmes in the first tranche in Sept-Dec 2020, this was due to confidence issues evident among several facilitators in relation to programme delivery online. This was improved upon in the second tranche in Jan-March 2021 with an uplift of two programmes and an average attendance of 8 participants.

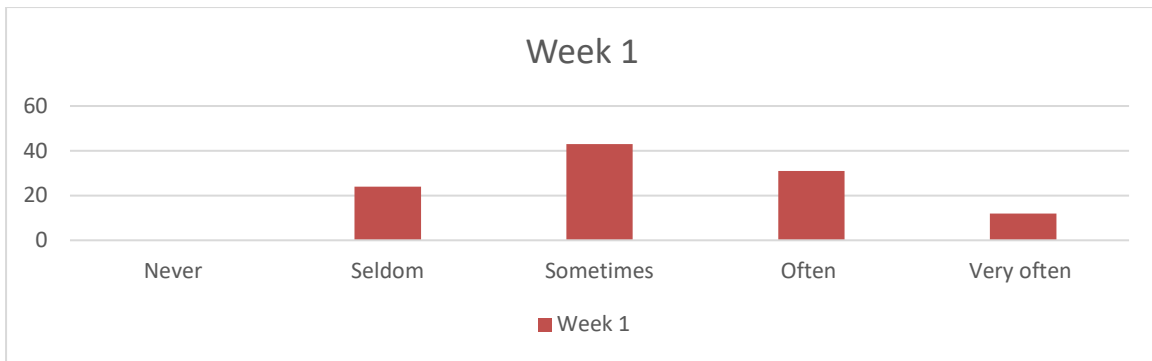
**Table 1 – Programme attendance 20-21**

Date	Number of Programmes	Number of Beneficiaries	Number completed	% Retention
<b>Sept-Dec 20</b>	19	110	91	82.73%
<b>Jan-March 21</b>	21	199	165	82.9%
<b>Totals</b>	40	309	256	82.8%

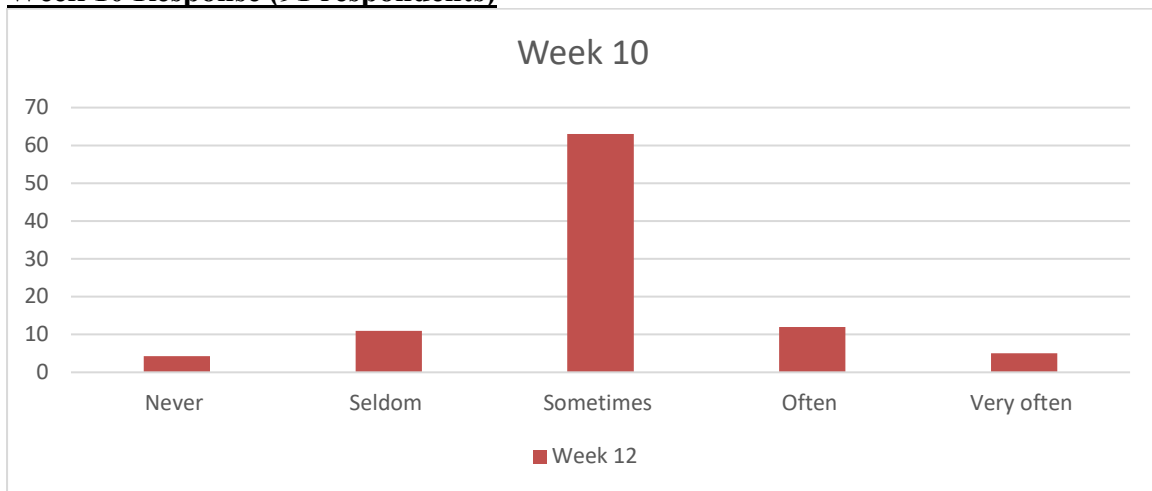
More significantly, the following tables will demonstrate the effectiveness of our pain support programmes in terms of improving the perception of participants in relation to their pain. Specifically, collated evidence from the Sept-Dec tranche demonstrates huge improvement in reducing preoccupation with opioid medicines, pain and discomfort reduction, reduction on reliance on pain medication and a huge increase in self-help activity/techniques other than medicine.

**In the past 30 days how much time was spent thinking about your opioid medications?**

### **Week 1 response (110 respondents)**

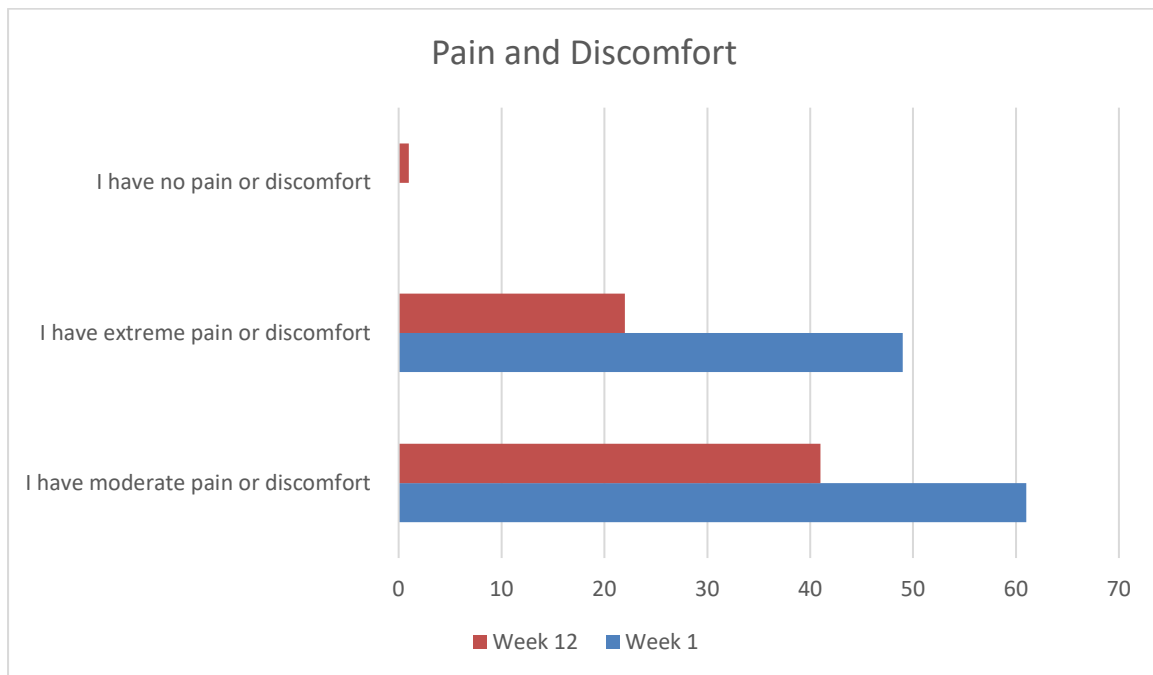


**Week 10 Response (91 respondents)**



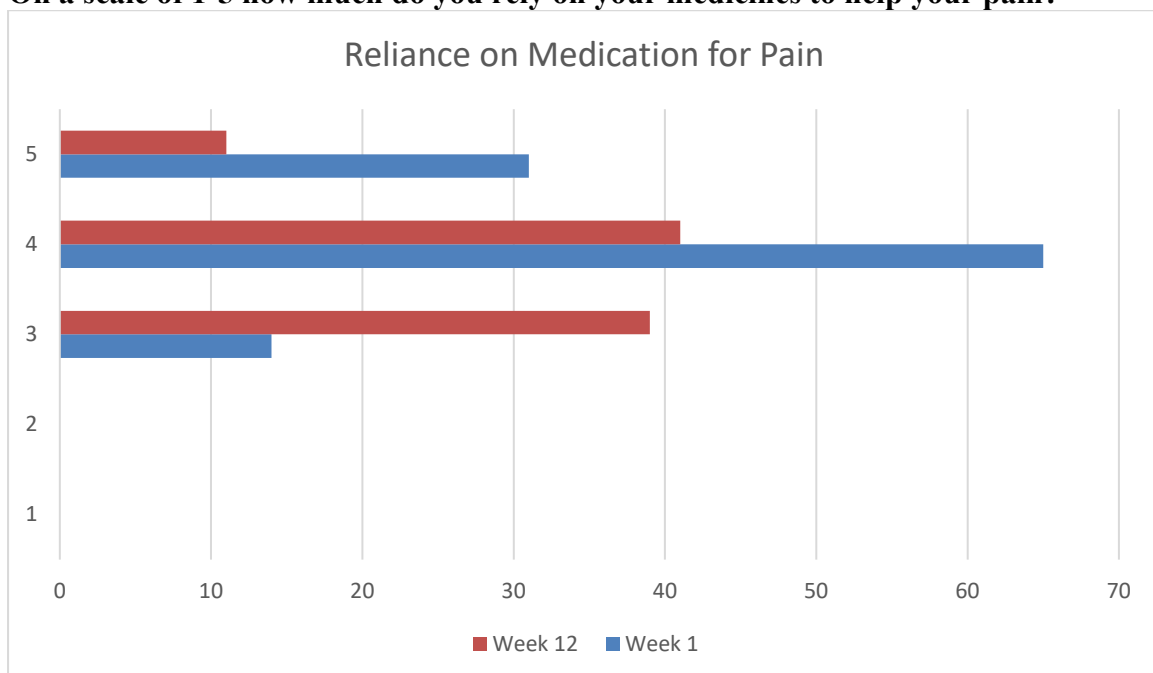
The above graphs demonstrate a dramatic drop in the number of participants' preoccupation with their opioid medication. Those in particular who thought often or very often about their medication were reduced from around 45 to almost single figures.

### Pain and Discomfort



The above ‘Pain or Discomfort’ graph demonstrates that the number of participants experiencing extreme pain or discomfort had been halved between week one and week ten, while those experiencing moderate pain had been reduced from 62 to 42.

### On a scale of 1-5 how much do you rely on your medicines to help your pain?

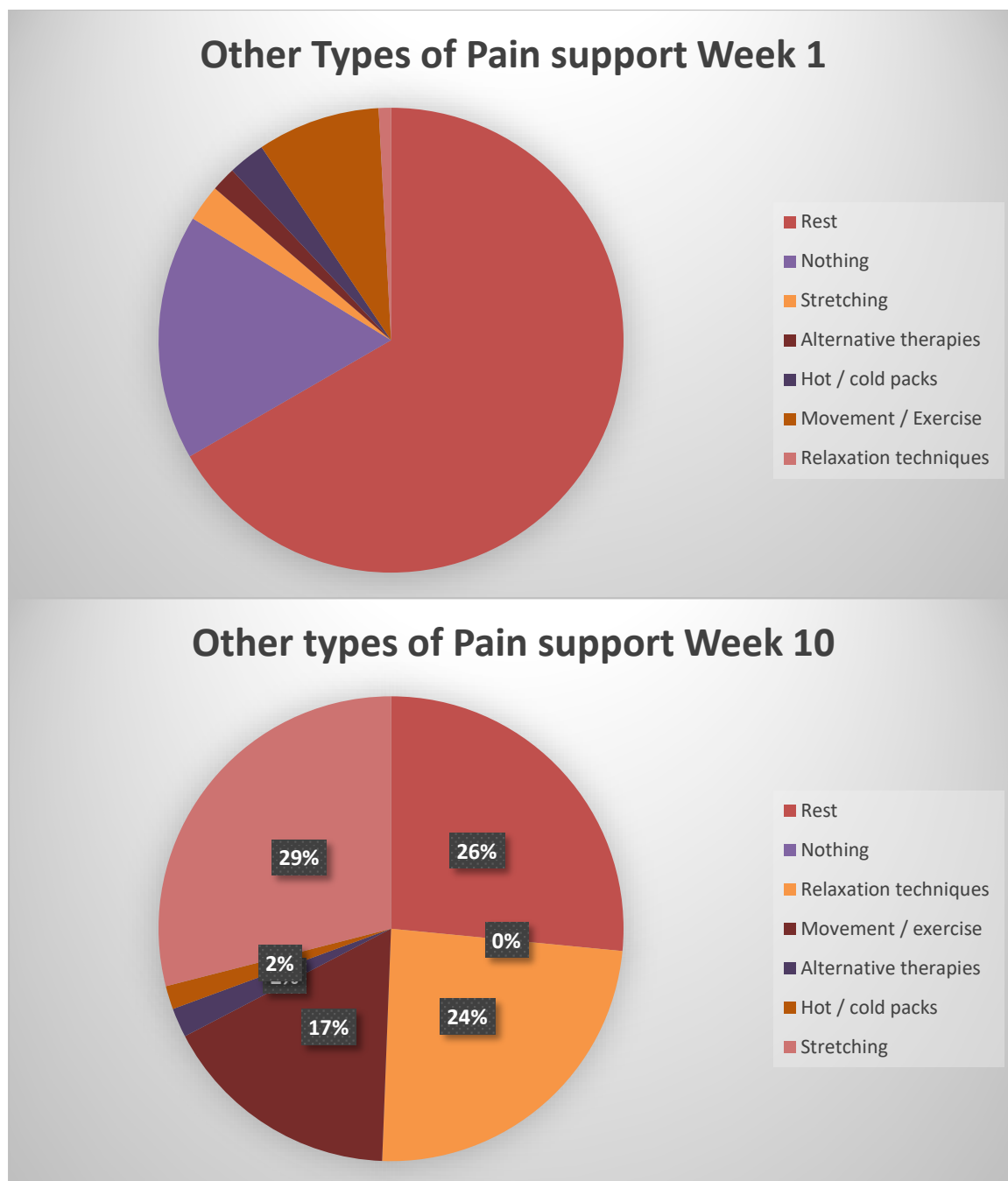


In terms of participants’ reliance on pain medication, those at point 5 on the 1-5 scale i.e., those relying heaviest on pain medication, had been reduced from 32 to 7 between week 1-10, those



on point 4 on the scale were reduced from 65 to 42, while there was a corresponding increase of participants on point 3 of the scale from 14 to 38.

**Apart from medicines what else do you do to help your pain?**



The above pie charts demonstrate the effect the programme has had on the enthusiasm of participants to engage in various types of activity to help them live better with pain.

- In week 1 around 80% either rested or did nothing to help live with pain; by week 10 rest has been reduced to circa 28% while those who did 'nothing' registered at 0%.

- In week 1 those engaging in Stretching, Alternative Therapies, Relaxation Techniques and Movement/Exercise amounted to 20%, while by week 10 this increased to around 75%.
- The above two points combined demonstrate that the vast majority of those who took part in the Better Days Pain Support Programme became more proactive in helping themselves to live better with their pain.

Quotes from participants:

*‘I found the course very informative and realistic and have reduced pain relief with analgesics significantly. It was facilitated by knowledgeable and empathetic leaders who treated the group with a lovely sense of respect. I learnt a lot and also had some information reinforced. I enjoyed the group participation and found other participant's input enriched the conversations.’*

*‘My pain had overwhelmed me and I had lost my confidence and drive. The course has built my confidence and improved motivation and self-worth. I have now a more positive outlook that has helped get back to work.’*

*‘I was newly diagnosed when I heard about the programme, it was a lifeline for me with no follow up info or support from GP surgery due to current pandemic situation. Before this programme I was frightened, worried and anxious about my future, now I feel informed and confident in being able to manage this condition going forward in the knowledge that I am part of a wider circle of support. I am not alone.’*

*“I found the programme very informative. The Tutors were both lovely and very knowledgeable. Right now, I have changed my medication as nothing is helping with my pain but I wouldn't have asked my GP for a review if it wasn't for doing this course. I understand a lot of chronic pain can come from your mental state and have now asked to be referred for a CBT course through work. Talking and listening to all the other people was so helpful and helped with me knowing I'm not suffering alone. There was a great variety of activities on the course which was fantastic to be given the opportunity to experience. I am aware that if I can just get my pain under control this will hopefully be half the battle. I do hope to stay in touch with everyone and see how they get on in the future. I wish them all the best. Thank you for providing this service it is an excellent service.”*

*“This programme opened my eyes to a lot of coping mechanisms for pain I can use instead of using medication only. It has reduced my reliance on pain medication which I would help with pain and sleep medication. I found the sleep tips and relaxation techniques have proved invaluable and I have implemented these into my daily life schedule. The nutrition session was always very useful and demonstrated the importance of eating a balanced diet which will have a direct impact on my health. I thoroughly enjoyed the course and would recommend it to friends and family who struggle with daily pain. Thank you everyone involved with the programme”.*

*“I found the programme very useful being able to talk with others with similar issues to myself, help me appreciate things more. I have learned new techniques and a realisation that I can only do what I feel able to and not to over exert just as I am having a good day. The leaders have been brilliant; each with their own skills and both very good communicators,*

*and the guest speakers all useful in varying levels, some more than others. I certainly feel a lot better for having taking part and would highly recommend it to others. An excellent programme”*

*“This programme has been unbelievable. I have enjoyed the experience so much and think it’s something that should be offered to people with any type of pain or worry. It's been the best 10 weeks; I have learnt so much from this course and have also gained so much knowledge that has made a huge difference in my pain and my life. I couldn't say enough good things about it. One of the best experiences I have had. Each week I looked forward to learning something and can't believe it's over. Thank you to Oak Healthy Living Centre; the change I have had is fabulous”.*

## **Conclusion**

The Covid 19 pandemic, as well as causing death and ill-health throughout the world, has led to everyday life being disrupted with social restrictions being introduced to minimise the spread of the virus. For those delivering health improvement services in any sector, social restrictions have had to be overcome, mostly by electronic means.

For the Better Days Pain Support Programme in 2020-21, the conversion from the tried and tested community development approach of providing pain support in Healthy Living Centres to electronic delivery had to be planned and executed meticulously. Key to this process were the Steering Group, the Pain Facilitators and the Beneficiaries. We all recognise that electronic delivery (via Zoom) is not as good or as enjoyable as direct delivery in Healthy Living Centres, where the social interaction is paramount, but as is evident from the testimonies of the beneficiaries, it was still possible to reach a high level of satisfaction and health benefit at the computer screen.

The Alliance delivered 40 programmes in 20-21 to a cohort of 309 adults experiencing chronic pain in the everyday lives from more than three months. Despite the programme being delivered by non-traditional means i.e. on computer screen, some 82% felt committed to stay to the end to achieve maximum benefit. This benefit is proven by the numbers and percentages of people whose:

- Preoccupation with their opioid medication had reduced
- Pain and discomfort had reduced
- Reliance on pain medication had reduced
- Take up of beneficial activities had increased

The above points, combined with the graphs and written testimonies of the beneficiaries, attest to the efficacy of the Better Days Pain Support Programme, delivered in very invidious circumstances by a team of very capable and committed Pain Support Facilitators and supported by the dedicated Pain Steering Group.

We therefore conclude that the training, preparation and delivery of the Pain Support Programmes in 2020-21, during the Covid 19 pandemic, has been successful.