

\*CHANGE PAIN®
Taking care of pain

#### The Pain Toolkit

#### ...is for people who live with persistent pain

A persistent pain problem can be difficult to understand and manage on an everyday basis. The Pain Toolkit is a simple information booklet that could provide you with some handy tips and skills to support you along the way to manage your pain. It is not meant to be the last word in pain self-management, but a handy guide to help you get started – all you need to be is willing to read it and take on board some of the suggestions.

Good luck!
Pete Moore

Pete Moore who has persistent pain, asthma and osteoarthritis, has put these tools together with the help of friends, family and healthcare professionals. These tools have helped many people and could also help you! www.paintoolkit.org

#### The Digital Pain Toolkit

To sign up to receive further handy tips and skills to self-manage your pain straight to your email account, please visit

#### www.changepain.com/en/pain-toolkit.

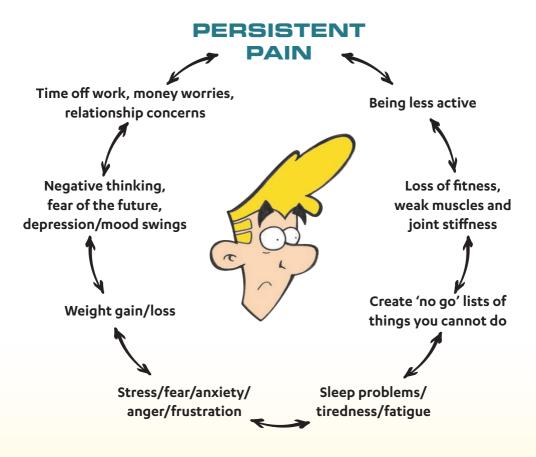
You can also open the camera on your phone and point it at the QR code here. This will automatically bring you to the registration page on the Pain Toolkit website.



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#### The Persistent Pain Cycle



Sometimes the arrows can also go anti-clockwise as well. For example, time off work can lead to negative thinking, fear of the future, which can lead to stress, fear etc.

## Do you feel trapped in a persistent pain cycle?

If so, ask yourself these three questions:

- 1. Do you do more on good days and less on bad days?
- 2. Are you an over achiever doing more than you have to?
- 3. Are you a people pleaser? Do you have a problem saying NO to others when you are asked to do things?

Could you see yourself in the persistent pain cycle and did you recognise yourself in the three questions above? If you did, then this Pain Toolkit could be for you, so please read on.

Persistent pain (sometimes called chronic or long-term) is...

Pain that continues for 3 months or more and may not respond to standard medical treatment. It can be disabling and frustrating for many people to manage. It can also affect relationships with family, friends and work colleagues. Sometimes people with persistent pain are told by healthcare professionals after assessment:



*"I am afraid you have a chronic or long-term pain problem. You will have to learn to live with it."* 

To date, your healthcare professionals may have done all that they can to help you and may have used many of the tools available in their toolkit. However there are so many things that you can do to help self-manage your pain with the support of your healthcare professional, family, friends and work colleagues. All you need is to be willing to ask for help.

#### Have you become a 'can't do' person?

A 'can't do' person is someone who has tried to carry out or take part in everyday tasks such as going to work, doing the house work, gardening, playing a sport, taking holidays, going to the cinema, eating out or taking part in family activities, but has stopped or given them up because of their pain. When this happens it is usual for your confidence levels to reduce. Is this ringing any bells? If you have reached this point you need to stop and take action.

By taking on board and practising the tools in the Pain Toolkit you could become a **'can do'** person again, but it could take time so please be patient with yourself.



Tuesday 3:30 pm

Look familiar?

#### Frequently asked questions

#### So is persistent pain a problem in Ireland?

The short answer is yes, so you are not on your own. Here are some alarming facts from Chronic Pain Ireland (www.chronicpain.ie).

There are an estimated 598,000 people with Chronic Pain in the Republic of Ireland. Approximately 20% are living with Chronic Pain at a severe to very severe level.



Why do I need to manage my pain? After all I see my healthcare professional and aren't they supposed to do that for me?

Many people with persistent pain see their healthcare professional for treatment, help and support. But have you actually estimated just how many hours during the course of a year you spend with your healthcare professional? It has been said that people with health conditions (including pain) may spend less than 3 hours a year on average in contact with a healthcare professional.



For the remaining 8,733 hours of the year they are on their own. So the need to learn pain management skills and incorporate them in their everyday activities is very important. As you can see, the need to become more involved in your own pain self-management is both necessary and important. It is certainly not all up to your doctor or healthcare professional to manage your pain. You have to play a vital part as well – it is all about teamwork.

Your next question may be... Well, how can I become more involved and how do I get started?

Using different skills and tools can be helpful. It is like a motor mechanic who has many tools in his/her toolbox to repair and maintain cars. People with pain also need a selection of tools to help them successfully self-manage it. You may not need to use all the tools suggested in the toolkit, but like any good motor mechanic it is best to have a variety of tools at the ready to use when and if they are needed.

Self-managing persistent pain is not as hard as you may think – so let's get started and look at the first tool in your new pain self-management toolkit.

MANAGEMENT

#### The Pain Toolkit



## Tool 1 – Accept that you have persistent pain... and then begin to move on

Acceptance is the first and the most important tool in your pain self-management toolkit. Acceptance is not about giving

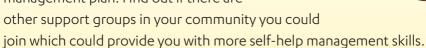
up, but recognising that you need to take more control with regards to how you can better self-manage your pain. Acceptance is also a bit like opening a door – a door that will open to allow you in to lots of self-managing opportunities. The key that you need to open this door is not as large as you think. All you have to do is to be willing to use it and try and do things differently.





#### Tool 2 – Get involved... building a support team

Being successful in pain selfmanagement means getting both help and support from others. Ask your healthcare professional, friends, family and work colleagues about working more together – becoming a team. Develop a pain selfmanagement plan. Find out if there are







Pacing daily activities is one of the key tools to self-managing your pain. You need to begin to pace your work and also other everyday activities. Did you recognise yourself from the pain cycle? You tend to over do things, or rest too much and become inactive and lose fitness. Pacing in short is: taking a break **before** you need it throughout the day. But how can you remember to pace yourself?

Remember the old saying...

'How do you eat an elephant?'
Answer: 'One bite at a time!' Pacing is carrying out activities one bite at a time, and not tackling all of them at once. For examples of pacing daily activities see page 18.







#### Tool 4 – Learn to prioritise and plan out your days

Prioritising and planning your days is an essential tool. Make a list of things you would like to do but remember to be flexible. It is a great way to set yourself a starting point.

#### **Examples:**

- Monday am vacuum the living room and have a couple of breaks so that I pace myself
- Monday pm prepare food for evening meal, sit down to do this
- Tuesday am go swimming, meet friend for a coffee/tea, practise some relaxation when I get home
- Tuesday pm I write an activity plan for the next day



#### Tool 5 – Setting goals / action plans

You may sometimes want to run before you can walk as that old saying goes. So to avoid this happening set yourself simple, realistic goals or action plans. Just as you need goal posts when playing football, or a finishing line when racing, you need something to aim for. Perhaps, you could set yourself a simple hourly, daily or weekly action plan. Always ask for help from your healthcare professional if you are not sure.



PLANNING



#### Tool 6 – Being patient with yourself

Take things steadily. It may take you a few weeks or months to see changes or improvements. When you start to feel good, you may want to catch up with activities that you may have let go of. Don't be tempted to over do it, otherwise your chances of yet another set-back could increase. A good saying is 'take things one day at a time'. And also... ask for help and support from others – it's not a sign of weakness, but a sign of strength!

#### Coping or self-managing?

Coping with persistent pain can be like playing a game of snakes and ladders – a game of luck. Being an over achiever you can tend to do more on good days (climb the ladder) and on bad days, do less and return to bed (slide down the snake). Self-managing is taking positive, planned action which can reduce the 'luck' element in pain self-management.



#### Tool 7 – Learn relaxation skills

Relaxation skills are very important for tense muscles in the body and for unwinding the mind. Relaxation could be:

- · Reading a book
- Listening to some music
- Gardening
- · Meeting friends for a coffee/tea
- Going to the cinema or a restaurant
- Belly breathing (your healthcare professional could show you how to do this)
- Meditation
- · Dancing
- Walking





#### Tool 8 – Stretching & exercise

Many people with pain fear exercise in case it causes more problems. However, regular stretching and exercising actually decreases pain and discomfort. It prepares the body for other activities. It can strengthen weak muscles and you will also feel better for it.

Remember to start slowly and build up or increase your stretching and exercising. It is not as hard as you think.



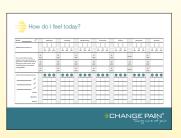
If you are in pain, remember that unfit and under used muscles feel more pain than toned ones. Talk with your physiotherapist or fitness coach about an individually tailored stretching and exercise programme that you can work on steadily and safely. This will help you build your confidence, muscle and joint strength. Remember that swimming (or just walking up and down in the pool) is also a low impact exercise and is good for you if you have joint problems. There are 15 good reasons why exercise is good for you on page 22.



#### Tool 9 – Keep a diary and track your progress

Keeping a diary of your progress will help you to see how far you have come and note the successes you have achieved. This will help you to build on success. But it is also handy to note what didn't work, so you can you learn from those experiences. We sometimes learn more from our errors and not

from our successes. Try to write down one piece of evidence each day to show yourself how you are positively self-managing your pain. Doing this has been shown to increase people's confidence. To download a free pain diary to track your progress, please visit www.changepain.com.





#### Tool 10 – Have a set-back plan

Is it realistic to think you will never have a set-back? The simple answer is NO! Developing a set-back plan is good pain self-management. Ask your healthcare provider if you need help in making one if you are not sure. Make a note of what triggered your set-back and what helped. This could be useful information if and when you experience another. There is an example of a set-back plan on page 19.





#### Tool 11 – Team work

Team work between you and your healthcare professional is vital. Imagine the Irish football team playing without a team plan. Managing your pain is not a 'one way street' and it is unrealistic for your healthcare professional to totally solve it.



You have an important part to play as well. Together both you and your healthcare professional can set an action plan. This action plan could help you to both track your progress. Action planning is taught when you attend a self-management programme.

## Tool 12 – is keeping it up... putting into daily practice the tools from 1-11

You may be asking yourself do I have to put these tools into daily practice? 'What, every day?' The simple answer is yes. Just as the person with diabetes has to take their treatment/medication and maintain their diet daily, your treatment is planning/prioritising, pacing, setting weekly or long-term goals/action plans, relaxation, exercise, generally keeping active and being in charge of your pain. Keeping it up is difficult for many people, but it's not as hard as you think once you have set yourself a routine. Just like brushing your teeth, self-managing your pain will become a habit. Get others involved and make pain self-management fun.

- · Pain acceptance
- Self-initiative
- · Set priorities
- Pacing
- Goals & action plans
- Patience
- Relaxation techniques
- Exercise
- Diary
- Plan B
- · and staying power!

It is not that difficult.



## Suggestions for your daily routine

Taking more responsibility yourself long-term in dealing with and managing your pain is not as difficult as you might think at the moment. If you develop a routine in using the tools, pain management will become routine – just like cleaning your teeth. Surround yourself with a team of people who will support you. Let other people be involved in your progress. Plan your pain management so that it is fun for you and people in your social surroundings.



What three things have I learnt about managing my pain in the Pain Toolkit?
1.
2.
3.
What will I try?
1.
1. 2.

The aim must be to get used to pacing yourself in all daily activities. You should always have your 'Tool 4' handy.

#### Ironing

As an alternative to doing a large amount in all one go, do smaller amounts frequently. Instead of doing the whole washing load of ironing at once, spread it over a period of days e.g. have two or three piles:

- an urgent pile,
- a not so urgent pile, and...
- an 'I can do that at the end of the week' pile.

#### **Shopping**

Instead of doing one large weekly shop, cut it down to a few trips to the shops per week. Divide your shopping into more bags, so that you are not lifting and carrying heavy bags. Remember to ask staff to help carry the shopping and put it in your car; remember to get someone (family or a neighbour) at home to lift and carry your shopping into the home. Or consider internet shopping, and then you just have to pack the items away once they have been delivered to your home.

These are just a couple of examples. There may be many other everyday activities that you need to think through before you tackle them. If you stop and think about what you intend to do **before** you do it, then there is less of a chance that you will have a set-back and in turn increase your condition.

#### Always bear in mind...

Remember pacing is 'taking a break **before** you need it' and spreading out your activities.



#### Tips for set-backs

It is not realistic to think that you will never have a set-back ever again. Remember if you are an over achiever, it is easy to forget to pace yourself and in turn you may experience a set-back. So the first thing not to do is panic, but many people do. It is best to have a set-back plan ready if one occurs. Set-backs are usually caused by doing too much — overdoing it, pressure from others, or just forgetting you have a pain problem. Don't get annoyed with yourself, it is common to occasionally have set-backs.

If you are not sure how to prepare a set-back plan, ask your GP or healthcare professional for help.

Don't forget to stretch before and after most physical activities to avoid a set-back!



- Thorough administration of medicines
- Scale down activities until the pain subsides
- Deliberately decline unimportant tasks that others would like you to do until you feel better
- Break up the tasks that you want to do into (even) smaller portions (see also Tool 4)
- Take sufficiently long breaks and periods of relaxation
- And... don't be either too proud or too scared to ask others for help



#### Prioritise your responsibilities

Pace yourself. Break up tasks into smaller portions. Rest in between. Reduce your activities until the set-back settles. Be kind to yourself. Say 'NO' to any unnecessary demands put upon you until you are feeling healthier. And... don't be to proud or scared to ASK for help!

#### Taking your medication

Follow or ask the advice of your GP or Pharmacist about medication and when you need to take it. If you have to take regular medication, think of ways to remind you to take it. Many people just simply forget. Use post-it notes, a timer or get someone to remind you. Please remember that taking medication if you have musculoskeletal pain (back, leg, arm, neck etc.) may mask the pain and encourage you to do more.

#### For musculoskeletal pain (back, leg, arm, neck etc.)

Apply heat and/or ice in a way that makes you most comfortable. To relieve initial pain, you could apply ice packs wrapped in damp towels for 5 minutes every hour for the first one or two days. Always make sure you have a cloth of some type between your skin and the ice, to prevent burning the skin and causing an ice burn. It is not recommended that you lie on an ice pack. (People with rheumatic problems may prefer to use heat rather than ice). Again, if you are not sure, seek advice from your GP or healthcare professional.



#### Take it easy

Briefly cut back on normal activities, lie down for a short while and relax but not for too long. Bed rest weakens muscle strength rapidly, you lose about 1% of total muscle strength a day if you become inactive – remember keeping active and mobile can actually speed your recovery.

#### Try to start moving gently

Remember to pace yourself. Begin gentle stretching and movement as soon as possible to regain normal suppleness. Keeping active may seem alien to you, but in pain self-management terms, learning to live with a persistent pain is a skill to be learned. Don't be put off – it does work!

#### Relaxation

Using relaxation is another good way of managing a set-back. Also accept the situation and that you are experiencing a set-back, and just as it came, it will go.

#### **Drinking water**

Water is essential for a healthy life, so drinking plenty of water is important for everyone. It's even more important if you are taking part in physical exercise, so make sure you keep properly hydrated before, during and after exercising.



# 15 reasons why stretching and exercising (don't forget swimming) is good for you

- 1. Helps to improve and maintain good overall health
- 2. Increases strong cardiovascular system heart lungs and blood vessels
- 3. Increases muscle strength
- 4. Improves flexibility
- 5. Increases endurance and stamina
- **6.** Increases natural pain killers (called endorphins) in the body's nervous system which help control pain
- 7. Helps with weight control
- **8.** Helps to improve quality of sleep
- 9. Helps balance and co-ordination
- 10. Reduces fatigue and increases energy
- 11. Reduces muscular tension, stress and depression
- 12. Helps combat depression and anxiety
- 13. Helps maintain a positive outlook
- 14. Helps to prevent constipation
- 15. Can be sociable



#### Making changes and becoming active

#### **Get Ireland Walking**

Get Ireland Walking is a national initiative that aims to maximise the number of people participating in walking – for health, wellbeing and fitness – throughout Ireland. Visit **www.getirelandwalking.ie**.

#### **Exercise programmes**

Sometimes it can seem like there are as many exercise programmes as there are different makes of cars on the road. Here are a few common ones:

- Yoga
- Tai chi
- Pilates

Please make sure that your teacher is qualified and experienced in teaching people with persistent pain. You should be encouraged to exercise at a pace that feels right for you.



#### **Body care**

Looking after your whole body is very important, so please think about:

- Eating healthy food
- Sleep sleeping only at night and avoiding cat naps during the day
- Hygiene washing and grooming your body daily

Looking after your body is very important and so it is vital that you look at what you put into it, that you get enough of the healthier types of food and the right amount of sleep and you also keep yourself clean.

## Useful websites for information and support

#### **Change Pain**

Change Pain's mission is to improve patient outcomes by improving pain management through adequate research, communication and education. **www.changepain.com** 

#### My Pain Feels Like

The 'mypainfeelslike...' initiative aims to improve the communication between patients and doctors. It provides resources and questionnaires to facilitate open discussion between Chronic Pain patients and their healthcare professionals. The 'mypainfeelslike...' website also provides resources to assist Chronic Pain patients to understand and manage their pain.

www.mypainfeelslike.ie

#### **Chronic Pain Ireland**

Chronic Pain Ireland (CPI) is the national charity providing information, education and support services to people living with Chronic Pain, their families and friends. They advocate on patients' behalf and work closely with all stakeholders. Their mission is to create a greater awareness of Chronic Pain and to provide relevant information and support for those living with the condition, for their families and friends.

www.chronicpain.ie



#### Additional useful resources

- Arthritis Ireland www.arthritisireland.ie
- Aware Depression Support www.aware.ie
- Diabetes Ireland www.diabetes.ie
- Endometriosis Association of Ireland www.endometriosis.ie
- **FibroIreland** www.fibroireland.com
- Health Service Executive www.hse.ie
- Irish Cancer Society www.cancer.ie
- Irish ME/CFS Association www.irishmecfs.org
- Migraine Ireland www.migraine.ie
- Multiple Sclerosis Ireland www.ms-society.ie
- Mental Health Ireland www.mentalhealthireland.ie
- Samaritans www.samaritans.org/?nation=ireland

#### About the author

## More about Pete Moore author of the Pain Toolkit and the motivational bit...

Pete lives in Essex and is a keen promoter of selfmanagement and other health conditions. Pete has written several pain self-management programmes and books. He is often asked to provide educational seminars for healthcare professionals and patient groups in the UK and Europe.



#### Pete is a member of the:

- · British Pain Society
- International Association Study of Pain (IASP)

#### Pete says:

"Self-managing a health problem is not as hard as you think and the best way to approach it is by taking small steps. Always ask for help and support from your healthcare professional, family, friends and work colleagues. In time you will become more confident and in control".

www.paintoolkit.org

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