Useful website links for information and support

Action on Pain www.action-on-pain.co.uk
American Chronic Pain Association
www.theacpa.org
Arthritis Care www.arthritiscare.org.uk
Arthritis Research Campaign www.arc.org.uk
BackCare www.backcare.org.uk
Breathworks Mindfulness based pain management
www.breathworks-mindfulness.co.uk
British Pain Society www.britishpainsociety.org
Depression Alliance www.depressionalliance.org
Expert Patients Programme www.expertpatients.co.uk
Healthtalkonline www.healthtalkonline.org **(patients experience self-managing with health problems)**
Fibromyalgia Association UK www.fibromyalgia-associationuk.org
ME Association www.meassociation.org.uk
Migraine Trust www.migrainetrust.org
MIND confidential help and advice on www.mind.org.uk
Multiple Sclerosis Society www.mssociety.org.uk
NHS Direct www.nhsdirect.nhs.uk **(Tel 0845 4647)**
NHS Choices www.nhs.uk
Overcoming mental health problems—one step at a time
www.overcoming.co.uk
Pain Association of Scotland www.painassociation.com
Pain Concern www.painconcern.org.uk
Pain Support www.painsupport.co.uk
Pain Relief Foundation www.painrelieffoundation.org.uk
Pelvic Pain Support Network www.pelvicpain.org.uk
Rheumatoid Arthritis Society www.rheumatoid.org.uk
Samaritans www.samaritans.org.uk
Stroke Association www.stroke.org.uk
Trigeminal Neuralgia Association UK www.tna-uk.org.uk

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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.

Tool 1 - Accept that you have persistent pain….and then begin to move on
Tool 2 - Get involved - building a support team
Tool 3 - Pacing
Tool 4 - Learn to prioritise and plan out your days
Tool 5 - Setting Goals/Action Plans
Tool 6 - Being patient with yourself
Tool 7 - Learn relaxation skills
Tool 8 - Stretching & Exercise
Tool 9 - Keep a diary and track your progress
Tool 10 - Have a set-back plan
Tool 11 - Team Work
Tool 12 - is keeping it up… putting into daily practice the tools from 1-11.

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!

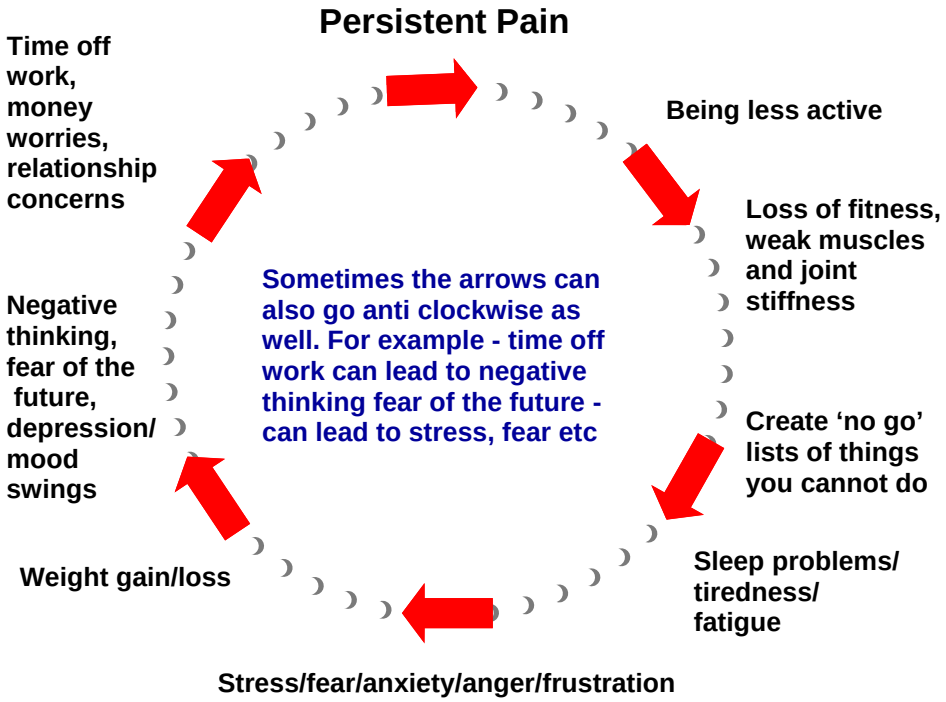
Pete Moore

petemoore2@yahoo.co.uk
www.paintoolkit.org

Pete Moore who has persistent pain, asthma and osteoarthritis, has put these tools together with the help of friends, family and health care professionals.
Special acknowledgement to the Bradford Pain Rehabilitation Programme team and NHS Kirklees.

These tools have helped many people and could also help you!

The Persistent Pain Cycle



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.

Using the Internet

I found the Healthtalkonline site very useful. It gave me the opportunity to hear, see and read about how others live with their pain. I now know I'm not on my own.
N.K. Somerset.

There seem to be a lot of websites that wanted to tell me that if I took this or did that, my pain would disappear. I now tend to only visit sites that use the org.uk, .nhs.uk, .gov.uk or ac.uk addresses. T.F. Essex

More about Pete Moore & Dr Frances Cole co- authors of the Pain Toolkit and *the motivational bit….*

Pete Moore

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

Pete is a member of the:

- British Pain Society
- International Association Study of Pain (IASP)
- European Federation for Research in Rehabilitation
- American Chronic Pain Association

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 health care professional, family, friends and work colleagues. In time you will become more confident and in control".*

Dr Frances Cole

Dr Frances Cole is a GP and Pain Rehabilitation Specialist and Cognitive Behavioural Therapist in West Yorkshire UK.

She is a member of the British Pain Society and co-author of the self help guide "Overcoming Chronic Pain".

Special thanks also to:- Dr Patrick Hill, Neil Berry, Dr Franz Gerstheimer and to the many other people who have made the production of the Pain Toolkit possible.

Feedback from people who have used the Pain Toolkit

Pacing

I found the 'pacing' tool most effective for me. I was one of those people who always did an activity until the pain became too excruciating and only then I would stop. Now that I pace my activities, I feel I can do more without the pain increasing. Keeping a pain diary also helped me to see where I was doing too much.
H.T. London

Acceptance...is the key

I didn't like that when I read it. Who was this Pete Moore telling me that I had to accept my pain? But when I sat down and thought it through, acceptance is the key to moving on and I now feel I have done that. By using some of the tools, I have got my family life back and even returned to work.
M.E. Chelmsford

Action Planning

For me everyday was the same. Get up, have breakfast, watch TV, have lunch, watch TV, the family would come home from work, watch more TV.

Learning to set simple action plans has helped me to break these boring habits. I now set simple goals so that I regularly stretch and exercise and of course include relaxation. Guess what? I now watch less TV. I feel more in control, and have less pain.
B.B. Essex

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.

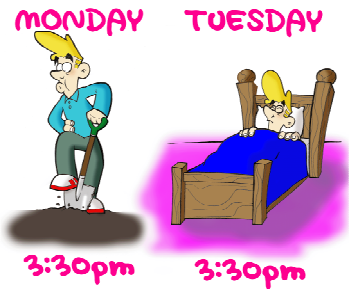
Sometimes people with persistent pain are told by healthcare professionals after assessment:

"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 health care 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.



Look familiar?

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.

So is persistent pain a problem in the UK?

The short answer is yes, so you are not on your own.

Here are some alarming facts from the Chronic Pain Policy Coalition **www.paincoalition.org.uk**

- *Persistent pain affects 7.8 million people of all ages in every parliamentary constituency of the UK. 70% or people with persistent pain are under 60 years old*

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

Many people with persistent pain see their health care 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 health care 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 health care 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.

So 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 health care professional to manage your pain. You have to play a vital part as well - it is all about teamwork.

Making changes and becoming active

GP Exercise on Referral
If you are unsure about becoming active or exercising, your GP can refer you to their GP Exercise on referral scheme. These types of schemes are run within local gyms and fitness centres and can include facilities for swimming. Ask at your GP surgery for more information and about other pain management support available.

Walking for health
Also find out more about 'Walking for Health'. These are usually run locally by your local Borough Council. Please also visit the Walking Health Initiative website. **www.whi.org.uk**

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

(pronounced Pil ar tes)

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 resources and choices to help you

Below are some choices to access support, advice or help in your area and nationally.

Self-management programmes (SMP)
These are run in the community by highly trained tutors who also have health conditions (including pain) themselves but have learned to become good self-managers. SMP's are run by **Arthritis Care** called Challenging Arthritis **www.arthritiscare.org.uk** and the **Expert Patients Programme** **www.expertpatients.co.uk**

NHS Pain Management Programmes (PMP'S)
PMP's are in some areas. Your GP can help you find a local PMP or go to:
www.britishpainsociety.org/patient_pmp.htm

Remember PMP's and SMP's can provide you with many self-management tools, *but you have to do the work*.

NHS Patient Advice and Liaison Service (**PALS)**
This service can provide information that may help you in locating other support services. You can contact them via your local NHS Primary (or Hospital) Care Trust or go to **www.pals.nhs.uk**

Utilising Community Resources
Your local library is a good starting point as they hold useful information (access to the internet, books, DVD's, CD's and cassettes) about other local health and community initiatives.

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.

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

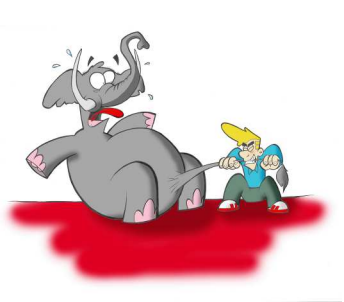
Being successful in pain self-management means getting both help and support from others. Ask your health care professional, friends, family and work colleagues about working more together - becoming a team. Develop a pain self-management plan. Find out if there are other support groups in your community you could join which could provide you with more self-help management skills.

Tool 3 - Pacing

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 12.

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

- ✓ Helps to improve and maintain good overall health
- ✓ Increases strong cardiovascular system – heart lungs and blood vessels
- ✓ Increases muscle strength
- ✓ Improves flexibility
- ✓ Increases endurance and stamina
- ✓ Increases natural pain killers (called endorphins) in the bodies nervous system which help control pain.
- ✓ Helps with weight control
- ✓ Helps to improve quality of sleep
- ✓ Helps balance and co-ordination
- ✓ Reduces fatigue and increases energy
- ✓ Reduces muscular tension, stress and depression
- ✓ Helps combat depression and anxiety
- ✓ Helps maintain a positive outlook
- ✓ Helps to prevent constipation
- ✓ Can be sociable

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..

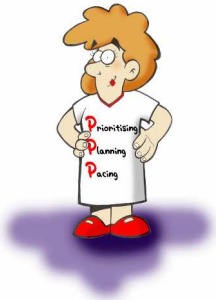
Please remember that taking medication if you have musculoskeletal pain (back, leg, arm, neck etc) may mask the pain and encourage you to do more.

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 health care professional*.

Take it easy.
Briefly cutback 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.



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 a.m. - vacuum the living room and have a couple of breaks so that I pace myself
- Monday p.m.- prepare food for evening meal - sit down to do this
- Tuesday a.m. - go swimming - meet friend for a coffee/tea - practise some relaxation when I get home.
- Tuesday p.m. - 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 health care professional if you are not sure. You can also learn more about setting goals and action planning when you attend a Self-Management Programme (SMP).

See page 16 for more information about attending an SMP.

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—its not a sign of weakness but a sign of strength!

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 heath care professional could show you how to do this)
- Meditation
- Dancing
- Walking.

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. (This is like sliding down the snake). Self-managing is taking positive, planned action which can reduce the 'luck' element in pain self-management.

Having a set-back plan
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.

Don't forget to stretch before and after most physical activities to avoid 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 health care professional 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.

Examples of pacing your daily activities

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...
- ✓ '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; remembering 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 every day 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.

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

Tool 8 - Stretching & Exercise

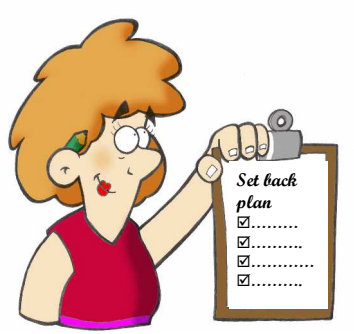
Many people with pain fear exercise in case it causes more problems. However this is not true. Regular stretching and exercising actually decreases pain and discomfort.
It prepares the body for other activities. It can strengthen weak muscles and you will also feel better for it. Remember to start slowly 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 15.

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 peoples confidence.



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 13.

Tool 11 - Team Work

Team work between you and your healthcare professional is vital. Imagine the Arsenal football team playing without a team plan.

Managing your pain is not a 'one way street' and it is unrealistic for your health care professional to totally solve it. You have an important part to play as well.

Together both you and your health care 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.

What three things have I learnt about managing my pain in the Pain Toolkit?

1. ……...
2. ……...
3. ……...

What will I try?

……

……

……