



Pete Moore is the author of the Pain Toolkit

He has persistent pain, asthma, prostate cancer and osteoarthritis.

He has put these tools together with the help of friends, family and healthcare professionals.

Make self-managing your pain, your first choice and not the last resort.

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Welcome to the Pain Toolkit

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.

Like many people I struggled to manage my pain back in the early 1990's. I was lucky to get myself on a pain management programme, which gave me the information, but more importantly, the confidence to manage my pain, myself.

Since 1997, I haven't had the need to take any pain medication, simply because I still use the information from the programme.

Is it easy? Well it's like most things, you have to work at it. I'm not an academic guy, but all I can tell you, is that if I can do it, then I know others can.

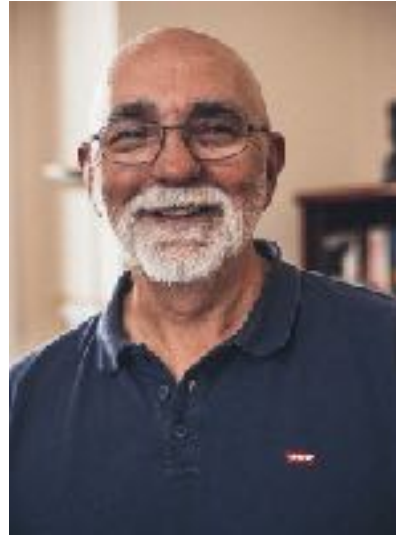
The Pain Toolkit is a simple information booklet that could provide you with some handy tips and skills to support you along the way to manage your pain.

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

12 Pain Toolkit Tools

- ◆ **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 setback plan**
- ◆ **Tool 11 Team Work**
- ◆ **Tool 12 Keeping it up...putting into daily practice the tools 1-11**

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Living with pain can be tricky and you may need some help, as I did at times. Where do you get help from? Well, help and support can come from your family, friends, healthcare teams, work colleagues and the Pain Toolkit.

Are any of these questions true for you?

- ✳ Does pain stop you from doing the things you enjoy?
- ✳ Do you struggle to understand your pain?
- ✳ Do you want your pain to stop controlling you?

If any of these questions are true, then this toolkit is for you!

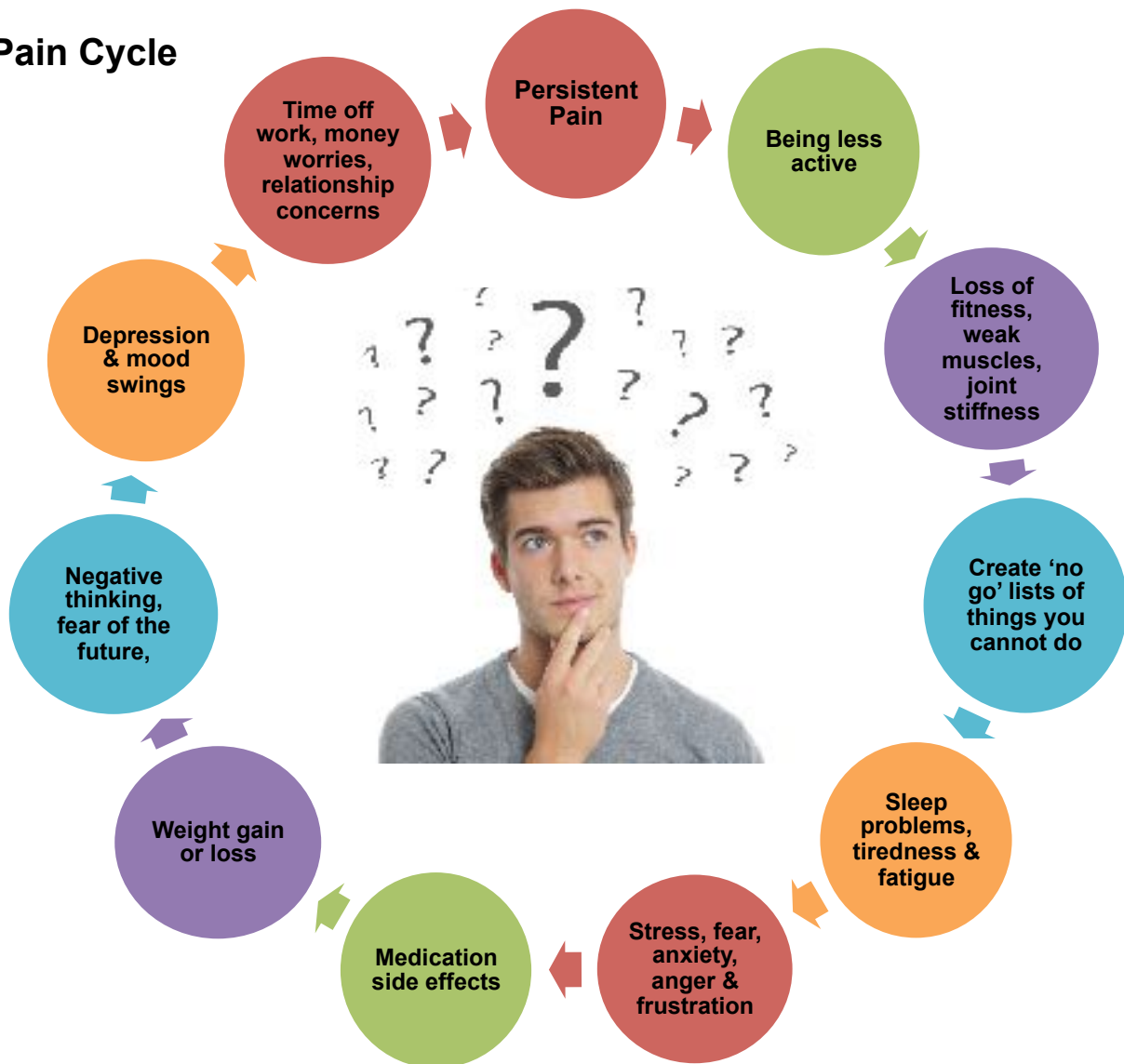
The Pain Toolkit is a simple guide that gives you some handy tips and skills to help you understand and manage pain better!

Your three step guide for the best use from the Pain Toolkit

1. Read it and show the Pain Toolkit to your circle of support, your partner, family, friends, work colleagues and your healthcare team.
2. Choose and circle only two or three tools you think will make a positive change to self-managing your pain. Ask for support and help from your support circle.
3. Once you feel confident with those tools, then do the same steps and choose another two or three tools. Repeat again when needed.

So now let's get started.... Explore the Pain Cycle on the next page.

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?

Did you see yourself in this cycle or the three questions? If you did, then this Pain Toolkit could be for you, so please read on.

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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 your 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.”*



“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.

Tip from Pete: Check out [Understanding Pain in less than five minutes video on YouTube](#). It shows and explains how pain works.

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.

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So is persistent pain a health problem in the UK?

The short answer is yes, so you are not on your own. Here are some worrying facts from the Chronic Pain Policy Coalition.



- Over **28 million people** live with persistent pain and one in four said pain had kept them from usual activities (including work) on at least 14 days in the last three months.
- Back pain alone is estimated to cost **£12.3 billion per year**.
- People with persistent pain were more likely to be anxious or depressed - 69% with severe pain are worried about their moods.

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 self-management skills and incorporate them in their everyday activities is very important.

So it is vital for you to manage your pain. Your doctor or healthcare team can support or guide you to manage it well.

Ask Pete

It's your chance to ask me anything on self managing pain. Use www.paintoolkit.org/contact. It will be honest, no-nonsense feedback. I will tell you if I do not know the answer. Of course, I **cannot answer** any medical questions.

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Your next question may be *“Well, how can I become more involved and how do I get started to?”*

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.

It is best to have a variety of tools ready to use if, and when needed just like a good car mechanic. Of course, you may not need to use all the tools suggested in the Pain Toolkit, just the ones that help you self-manage better.

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. It is recognising that you need to take more control and find how you can self-manage your pain better.



Acceptance is also a bit like opening a door - a door that will open to allow you into 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.

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Tool 2 - Get involved - building a support team

Being successful in pain self-management 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 self-management plan. Find out if there are any support groups in your community or online you could join which could provide you with more self-help management skills.

Tool 3 - Pacing

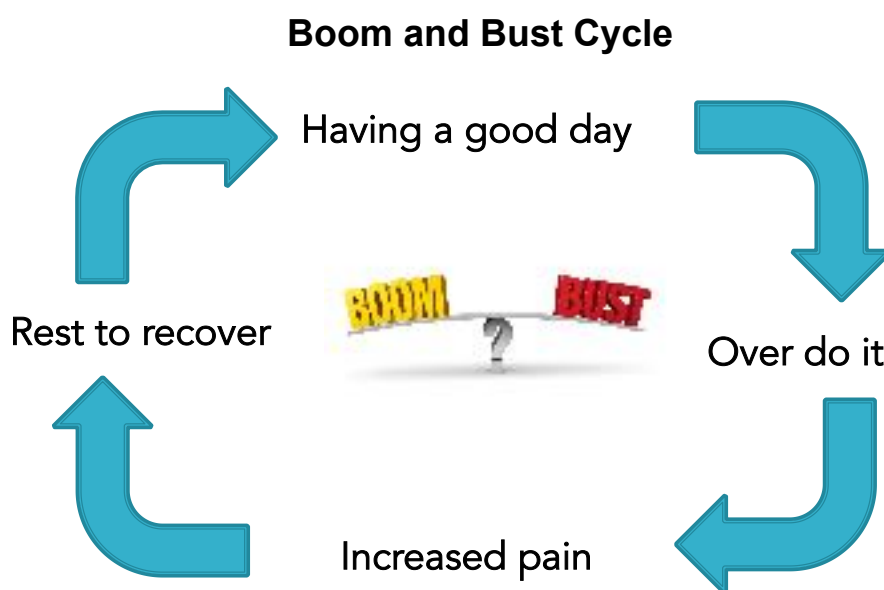
Pacing daily activities is one of the key tools to self managing your pain. You need to begin to pace your work and also other everyday activities. Can you recognise yourself in the Boom and Bust cycle? Are you doing too much on your 'good' days, and less on your bad ones.

Pacing in short is: taking a break before you need it throughout the day.

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 14.



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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.

- 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, 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 every day. It can increase your confidence

Perhaps, you could set yourself a simple hourly, daily or weekly action plan. If you are not sure how to do so and need more help, then ask for support from your healthcare team.



Stretching and Exercising "I was frightened to exercise as I thought I would do more damage. Pete talked about the importance of stretching first before exercising, and it made sense. I liked the link to the **NHS Fitness Studio** and I take part in many of the classes" F.N.

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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.

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
- ✦ Relaxation exercises
- ✦ Meditation (**Mindfulness**)
- ✦ 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.

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Tool 8 - Stretching & Exercising

Many people with pain fear exercise in case it causes more problems, like increasing their pain. 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 feel better for it. Remember to start slowly. It is not as hard as you think. **Cats and dogs stretch, every time they get up. Why? Because they are preparing bodies for movement.**

If you are in pain, remember unfit and under-used muscles feel more pain than toned ones. Talk with your physiotherapist or fitness coach about developing a tailored stretching and exercise programme that you can work on steadily and safely. This will help build your confidence as well as muscle and joint strength. Remember that swimming (or just walking up and down in the pool) is 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 17.

Try out the NHS Fitness Studio on NHS Choices. It's very visual, has no membership fee and open 24hrs.

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 learn from those experiences. We sometimes learn more from our errors and not from our successes.



Personally, I found keeping a diary showed me how well I was doing in self-managing my pain.

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Tool 10 - Have a setback plan

Is it realistic to think you will never have a setback?

The simple answer is NO! Developing a setback 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 setback and what helped.



This could be useful information if and when you experience another.

There is an example of a setback plan on Page 15.

Tool 11 - Team Work

Team work between you and your healthcare team is vital. Imagine the Arsenal football or any 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 pain or self-management programme.



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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?

.....

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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 pain.



Remember pacing is ‘taking a break before you need it’ and spreading out your daily activities.

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Having a setback plan

It is not realistic to think that you will never have a setback ever again. Remember if you are an over achiever; it is easy to forget to pace yourself and in turn you may experience a setback.

So the first thing not to do is panic, but many people do. It is best to have a setback plan ready if one occurs.

Setbacks are usually caused by doing too much – overdoing it, pressure from others, or just forgetting you have a pain problem. Try not to get annoyed with yourself, it can cause more stress and pain.

If you are not sure how to prepare a set-back plan ask your GP or healthcare 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 too 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.



Don't forget to stretch before and after most physical activities to avoid a setback.

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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 cutback on normal activities, lie or sit 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 setback. Accept it is just a setback, and as it came, it will leave.

Check out the website Living with Pain www.paincd.org.uk for free downloadable simple relaxation skills/techniques.

Retrain Pain

A free on-line course in various languages, to help self-manage your pain. The course is free, and is viewed entirely online. It is recommended you view it slowly, in small sections. This allows time to review and apply the material. www.retrainpain.org

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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 your muscle strength
- ☑ Improves your flexibility
- ☑ Increases your endurance and stamina
- ☑ Helps to improve quality of sleep
- ☑ Helps with your balance and co-ordination
- ☑ Reduces your fatigue and increases energy
- ☑ Reduces muscular tension, stress and depression
- ☑ Helps to combat depression and anxiety
- ☑ Helps to maintain a positive outlook
- ☑ Helps to prevent constipation
- ☑ Can be sociable
- ☑ Increases natural pain killers (called endorphins) in the bodies nervous system which help control pain
- ☑ Helps with weight control



Pete walking across The Essex way (133km) in 2006. It took him 10 months.

Why? Because he paced himself.

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.

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Useful resources and choices to help you

Self-management programmes (SMP's)

These are run in the community by highly trained tutors who also have persistent health conditions themselves but have learned to become good self-managers. SMP's are run by Arthritis Care and Expert Patients Programme.



NHS Pain Management Programmes (PMP'S)

are run by a multidisciplinary team of health care professionals, supporting people with pain, to learn extra skills to self-manage their pain, and available in most areas of the UK. (**message from Pete.** "I went on a PMP in 1996, and it turned my life around. If you have the opportunity to attend a PMP, then do so.")

Your healthcare team can help you find a local PMP. Remember PMP's and SMP's can provide you with many self-management tools, **but you have to do the work.**

Health Talk on Line have a great website to read, hear and see people experiences living with pain. **www.healthtalk.org**

NHS Choices is the online 'front door' to the NHS. It is the UK's biggest health website and gives all the information you need to make choices about your health. **www.nhs.uk** (**Tip from Pete** "I use it all the time".)

Finding Community Resources Your local library is a good starting point as they hold useful information (access to the internet, books, DVD's & CD's) about other local health and support in your local area.

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Making changes and becoming active

GP Exercise on Referral

If you are unsure about becoming active or exercising, your healthcare team can refer you to an 'exercise programme to suit you.

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.

Exercise programmes. 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.

Good web sites to visit for getting active / exercise:

- ◆ **Get a life - get active**
- ◆ **Walk 4 Life**
- ◆ **NHS Fitness Studio** (open 24hrs and free)

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. .



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Pain and Sleep

People who read the Pain Toolkit have been asking for more information about how to deal with pain and sleep.

What keeps you awake and what helps you sleep.



Things that help too are relaxation and “belly” breathing from the stomach as well as exercise, stretching and being active through the day. Moods like depression and anxiety cause sleep problems too. Explore with your support team, GP or clinical team ways to help.

CBT talking therapy can help get better sleep and moods, so visit www.iapt.nhs.uk or www.nw.nhs.uk/pic/selfhelp for great resources and help.

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Pain & Work - handy tips from Pete



Pain and returning to work for some people with pain is tricky and many employers sometimes don't understand the challenges they have. Some people have to give up work because of their pain. I'm still working in spite of my pain...

The main thing to remember is to be honest about the difficulties you may have at work with your boss. Work out an action plan with them how you can carry out your duties, perhaps differently to others.

Taking more regular breaks may mean, you may have to add on extra time to your usual working day to others.

I would like to return to work but my pain stops me... Many people have to give up work because of their pain, but it's really important to look for other types of work that will suit you and your pain. I know it may sound odd, but working is actually good for us so we can interact with others and can provide you and your family with an income.

It is well-known that pain can make many people feel isolated and out of touch and the more time you spend off work, the harder it is getting back. Try to avoid waiting for your pain to be completely gone before you start work, it's unrealistic thinking.

Handy tip... For many people, being self-employed (being your own boss) suits people with pain because it provides them with flexibility as to how they work. They can set their own timetable, when they start and finish work and take breaks when they want or need to.

What work could you do...? That is up to you, and as always, speak to others to discuss your ideas. It could be an exciting prospect to do work you have always wanted to do, but never thought the opportunity would come around. I used to be a driving instructor, but always wanted to write. In my case, pain has given me the opportunity to do just that.

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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

Handy Tip:

Don't forget to show the Pain Toolkit to your doctor and other members of your healthcare team.

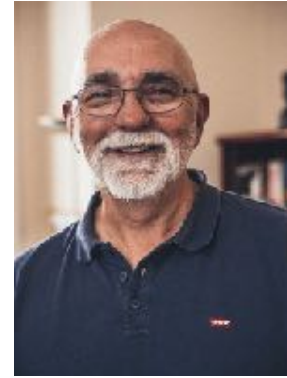
It is always best to work as a team with your healthcare professionals.



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About Pete Moore, author of the Pain Toolkit and the motivational bit....

Pete lives in North East Essex, in the UK and is a keen promoter of self-management and other health conditions. Pete has written several pain self-management programmes and books.



Pete Moore

He is often asked to provide educational seminars for healthcare professionals and patient groups in the UK, Europe and around the world.

Memberships etc...

- **British Pain Society (Honorary Member)**
- **International Association for the Study of Pain (IASP)**
- **Presenter at European Pain Federation (EFIC) Pain School**
- **EFIC Patient Liaison Group**

Follow me on **Twitter**  @paintoolkit2

Pete says *“Self-managing pain or a health problem is not as hard as you think and the best way to approach it is by taking small steps. Be patient with yourself. We as they saying goes ‘we want to walk before we can run’. Easy does it. You will get there.*

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”.

Special thanks to Dr Frances Cole who co-authored the Pain Toolkit and to all the healthcare professionals and patient groups who support pain self-management.



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Useful website links for more information and support

IMPORTANT: All the links below are to non-commercial organisations. Please remember to discuss with your doctor or healthcare professional before trying a treatment or procedure.

Arthritis Care

www.arthritiscare.org.uk

Arthritis Research Campaign

www.arc.org.uk

British Pain Society

www.britishpainsociety.org

Complex Regional Pain Syndrome

www.crps-uk.org

Depression Alliance

www.depressionalliance.org

Fibromyalgia Action UK

www.fmauk.org

Get a life

www.getalifegetactive.com

Health talk online

www.healthtalkonline.org

ME Association

www.meassociation.org.uk

MIND confidential help/advice

www.mind.org.uk

Migraine Trust

www.migrainetrust.org

Multiple Sclerosis Society

www.mssociety.org.uk

National Rheumatoid Arthritis Society

www.nras.org.uk

NHS Choices

www.nhs.uk

Overcoming health problems

www.overcoming.co.uk

Pain Support

www.painsupport.co.uk

Pain Relief Foundation

www.painrelieffoundation.org.uk

Pain Association Scotland

www.painassociation.com

Pain Concern

www.painconcern.org.uk

Pain UK

www.painuk.org

Pelvic Pain Support Network

www.pelvicpain.org.uk

Rheumatoid Arthritis Society

www.nras.org.uk

Stroke Association

www.stroke.org.uk

Shingles Support

www.shinglessupport.org

Trigeminal Neuralgia Association

www.tna-uk.org.uk

Sheffield Persistent Pain

www.sheffieldpersistentpain.com



www.facebook.com/PainToolkit