

PAIN TOOLKIT



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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.

It is a guide to help you get started and is not meant to be the last word in self-management.

All you need to be is willing to read it and take on board some of the suggestions.

Good luck!

Pete Moore

Pete Moore has persistent pain, asthma and osteoarthritis and has put these tools together with the help of his friends, family and healthcare teams.

Special acknowledgement to the Bradford Living with Pain Team

Welcome to the Pain Toolkit

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.



Pete Moore

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!

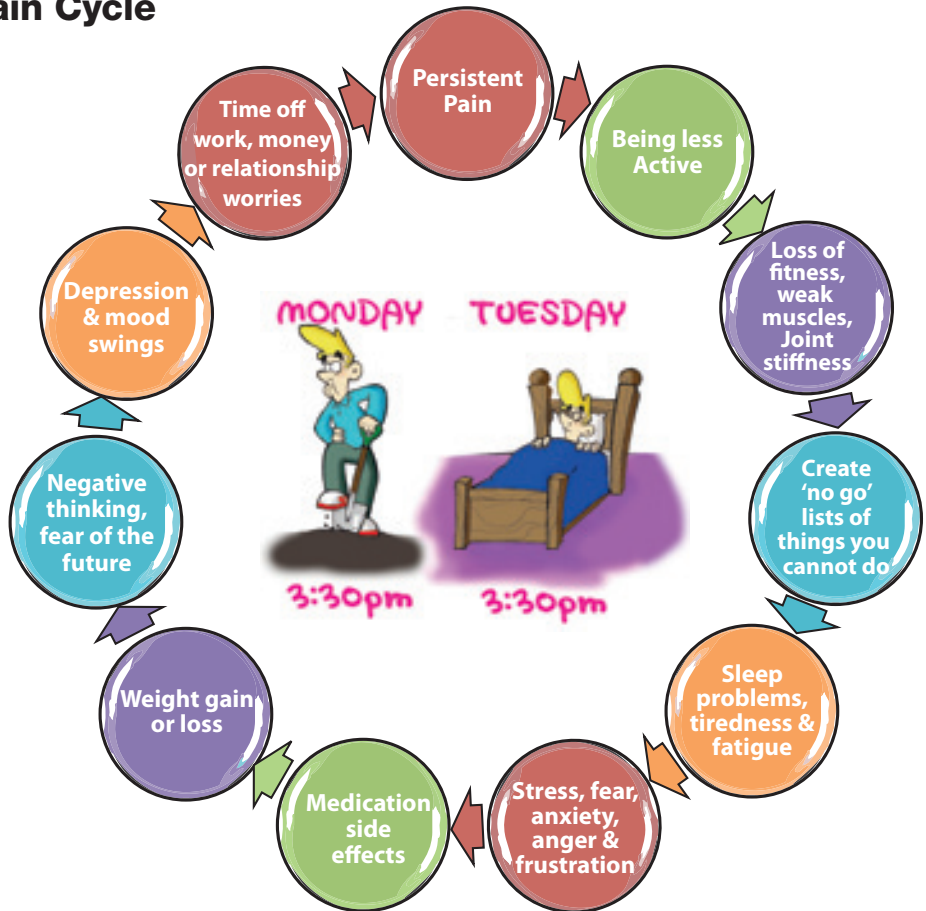
The Pain Toolkit is a simple guide that gives you some handy tips and skills to help you understand and manage pain better!

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.
- It's easy and not as hard as you think...

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

Pain Cycle



Do you feel trapped in a pain cycle like this?

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.

Persistent pain (also called chronic or long-term pain) is:-

Pain that continues for 3 months or more and may not respond to usual medical treatment. It can be disabling and frustrating for many people to manage. It can also affect relationships with their family, friends and work colleagues.

Sometimes people with persistent pain are told by their healthcare team after assessment: *“I am afraid you have a chronic or long-term pain problem. You’ll 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, their healthcare team may have done all that they can to help them.

They may have used many of the tools available in their toolkit. However there are many things that you can do to help self-manage your pain with the support of your healthcare team, 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 like going to work, doing housework, gardening, playing a sport, taking holidays, going to the cinema, eating out or taking part in family activities and 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 can become a ‘can do’ person. It could take time, so please be patient with yourself.

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 current facts from the Chronic Pain Policy Coalition.
www.policyconnect.org.uk

- Over **14 million people** live with persistent pain and one in four said pain 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 team and aren't they supposed to do that for me?

Many people with persistent pain see their healthcare team for treatment, help and support.

It's been said that people with health conditions like pain spend less than **three hours a year** in contact with their healthcare team/s. So in the other **8757 hours** of the year it is important that you learn to use and practise pain self-management skills.



So it is vital for you to manage your pain. Your doctor or health care team can only 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/ask-pete. 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.

Your next question may be “Well, what do I need to get started then?”

Using different skills and tools can be helpful. It's 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 their pain.

It's 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 use 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 better self-manage your pain.

Acceptance is a bit like opening a door - a door that will open to allow you into lots of self-managing opportunities. The key 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 healthcare team, friends, family and work colleagues about working more together - becoming a team.

Find out if there are any support groups in the community or online you could join to help build up your confidence and your range of self-help management skills.

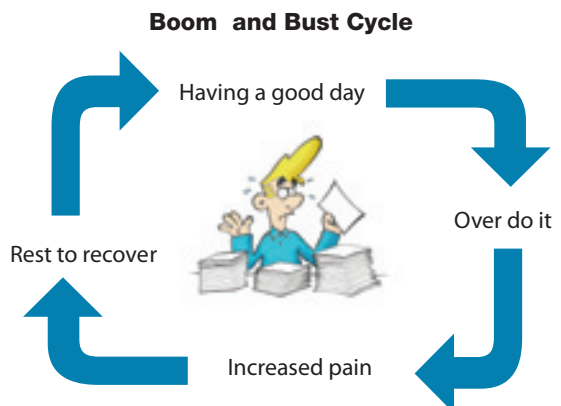
Tool 3 - Pacing

Pacing your daily activities is one of the key tools to self-managing your pain. You need to begin to pace your work and other everyday activities. Can you recognise yourself in the Boom and Bust cycle below? 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 to 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 13.



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 and remember to be flexible. It is a great way to set yourself a starting point. Here is an example;

- 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. - 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 really 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.



Pain Toolkit App to explore

Yes, there's also an (interactive) Pain Toolkit App where you can track your progress on your own and with your healthcare team. See Page 22 for more details.



Tool 6 - Being patient with yourself

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

Tool 7 - Learn relaxation skills

Relaxation skills are very important for tense and painful muscles in the body and for unwinding the mind.

Relaxation could be:

- Reading a book
- Listening to some music
- Gardening
- Meeting with friends for a coffee/tea
- Going to the cinema or restaurant
- Relaxation exercises
- 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.

Tool 8 - Stretching & Exercise

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 16.

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 keep a track of what you have achieved. It's also handy to note what didn't work so well as sometimes we discover more from our mistakes than our successes and make more progress.

Personally, I found keeping a diary showed me how well I was doing in self-managing my pain. It also highlighted things I was doing that that didn't work well, and so I was able to change how to deal with them more positively.



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 team if you need help in making one if you're not sure. Make a note of what triggered your setback and what helped you to recover. This could be useful information if and when you experience another.



There is an example of a setback plan on Page 14.

Tool 11 - Teamwork

Teamwork between you and your support team 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 to expect your GP or clinical team to solve or fix it.

Together both you and your support team can set an action plan. The action plan could help you to track your progress.

Action planning is taught when you attend a self management programme.



The Pain Toolkit - animated video is on YouTube. It describes the 12 Tools, and is introduced by Pete Moore

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, everyday?” 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, yet 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, then you can pack items away at your own pace after the delivery 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 setback and increase your pain.

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

Having a setback plan

It's not realistic to think that you will never have a setback ever again. Remember if you are an over achiever, it's easy to forget to pace yourself and end up with yet another setback.

Firstly try not to panic, many people do. It really helps to have a setback plan ready to use when they happen. 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 pain and stress.



Pete's Tip:

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

Some more ways to manage pain and setbacks

Prioritise your responsibilities.

Pace yourself. Break up tasks into smaller portions and be careful about **'must-do' or 'must get done' thinking.**

Rest in between. Reduce your activities until the setback 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 from others!

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 do forget. Use "sticky notes, in helpful places", a timer, a mobile phone, get someone to remind you or ask your chemist for a dosette box.

Medication for musculoskeletal pain like back, leg, neck, arm may lessen the pain and sometimes lead to over pacing.

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 instead 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 an ice burn to the skin. It is not recommended that you lie on an ice pack. (People with rheumatic problems may prefer to use heat rather than ice). Ask for advice from your healthcare team if you are unsure.



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 each 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 really 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](http://www.paincd.org.uk) www.paincd.org.uk for free downloadable simple relaxation skills/techniques.



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

- ✓ Helps to improve and keep good health.
- ✓ Helps build a strong heart and lung system
- ✓ Increases your muscle strength
- ✓ Improves your flexibility and suppleness
- ✓ Increases your stamina (so do things for longer)
- ✓ Increases natural pain killers (called endorphins) in the pain nerve system to control pain better
- ✓ Helps with weight control
- ✓ Helps you sleep better
- ✓ Helps your balance and co-ordination
- ✓ Increases your energy, fitness and reduces tiredness
- ✓ Reduces muscle tension and stress
- ✓ Helps deal with moods, depression, stress and anxiety
- ✓ Helps to maintain a positive outlook
- ✓ Often helps prevent constipation
- ✓ Can be sociable for you



Pete walking across The Essex Way (133km) in 2006.

Choose and circle two or three from the 15 reasons why exercise is important for yourself.

Handy Tip from Pete: I also found that cycling was an excellent way to exercise, especially when my arthritis was playing-up in my feet.

Drinking water

It is important if you are taking part in physical exercise to make sure you keep properly hydrated drinking water before, during and after exercise.

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 healthcare professionals, supporting people with pain, to learn extra skills to self-manage their pain and are 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 chance to attend a PMP, then grab it.")**

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.

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. **(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.

Making changes and becoming active

GP Exercise on Referral

If you're unsure about becoming active or exercising, your healthcare team can refer you to their '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.

Exercise programmes. Here are a few common ones:

- **Yoga** helps flexibility, stamina, memory and lessens stress
- **Pilates (pronounced Pil ar tes)** helps strength, flexibility and stamina
- **Tai Chi** helps with balance

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**
- ◆ **NHS Fitness Studio** (open 24hrs and free)
- ◆ **Exercise Works**
- ◆ **Walk 4 Life**

Body care:

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

- Eating healthy food (Mediterranean diet)
- 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 to help it manage better. It is vital you get enough healthy types of food, enough relaxation and sleep and take care to keep yourself clean.

Pain and Sleep - What keeps you awake and what helps you sleep?



People who read the Pain Toolkit have been asking for more information about how to deal with pain and 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.ntw.nhs.uk/pic/selfhelp for great resources and help.

Pain & Work - handy tips from Pete

Pain and returning to work for some people is really tricky and many employers sometimes don't understand these challenges. 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 on how you can carry out your duties, perhaps in different ways to others.

You may need to add on extra time to your working day as taking extra regular breaks helps. Telling others who work with you will help them to know what you are doing and why.

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. The more time you spend off work, the harder it is getting back. It is unrealistic thinking to wait for your pain to be totally gone before you return to, or start work.

Handy tip...For many people, being self-employed (being your own boss) can help some people, as it gives them flexibility about 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, yet 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 chance to do just that with great benefits.

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 diary also helped me to see where I was doing too much. *H.T.*

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? When I sat down and thought it through, acceptance is the key to moving on. I now feel I have done that. By using some of the tools, I have got my family life back and then a new job. *M.E.*



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.*

Different versions and translations of the Pain Toolkit can be seen here www.paintoolkit.org/download

Using the Internet

Pete says...

Type in **pain** to a search engine and around 810,800,000 results will come up. Most will try and sell you something. Always discuss with your healthcare team if you are going to try something. Remember, successful pain self-management is teamwork.

“I found the **Health Talk on-line** 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.*

“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.*


Pain Toolkit App

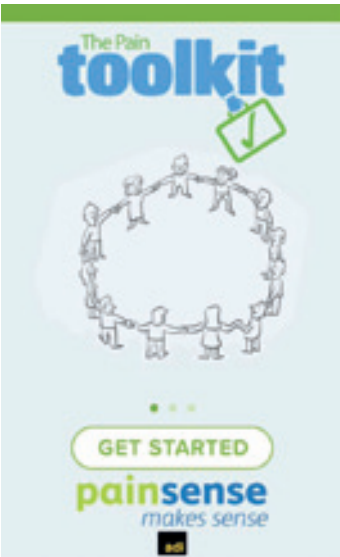
Yes, there is a Pain Toolkit App which people can download if you have a smart phone or tablet. And yes, it’s really easy to use!

Is the App different to the Pain Toolkit booklet?

Yes, it is animated and helps you track your progress and remember successes. It helps have setback plans ready, remind about medication and share changes with your healthcare team.

How and where do I download it from?

Download the App from the Apple App store or Google Play store. Search for Pain Toolkit and look for this icon 



I love the pain Toolkit App. It’s easy to use. It’s interactive and I can use it with my GP or on my own. N.N. Essex

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

Pete lives in Essex, and is a keen promoter of pain 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)

Follow Pete 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. As that saying goes ‘we need to walk before we can run’. Easy does it. You will get there.

Always ask for help and support from your healthcare team, family, friends and work colleagues. In time you will become more confident and in control”.



Peter Moore



Dr Frances Cole

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

She belongs to British Pain Society and co-author of the CBT self help guide “Overcoming Chronic Pain”. (ISBN 1841199702) now in the book list advised by Reading Agency 2013 for health and for libraries.

Our special thanks to all the health care professionals and teams and patient groups who support pain self-management.

Useful website links for more information and support

Arthritis Care

www.arthritiscare.org.uk

Arthritis Research Campaign

www.arc.org.uk

British Pain Society

www.britishpainsociety.org

Depression Alliance

www.depressionalliance.org

Exercise Works

www.exercise-works.org

Get a life

www.getalifegetactive.com

Health talk online

www.healthtalkonline.org

Know Your Own Health

www.kyoh.org

Fibromyalgia Association UK

www.fibromyalgia-associationuk.org

ME Association

www.meassociation.org.uk

Migraine Trust

www.migrainetrust.org

MIND Confidential Help/Advice

www.mind.org.uk

Multiple Sclerosis Society

www.mssociety.org.uk

NHS Choices

www.nhs.uk

Overcoming Health Problems

www.overcoming.co.uk

Pain Concern

www.painconcern.org.uk

Pain Support

www.painsupport.co.uk

Pain Relief Foundation

www.painrelieffoundation.org.uk

Pain UK

www.painuk.org

Pelvic Pain Support Network

www.pelvicpain.org.uk

Rheumatoid Arthritis Society

www.nras.org.uk

Sheffield Persistent Pain

www.sheffieldpersistentpain.com

Stroke Association

www.stroke.org.uk

Shingles Support

www.shinglessupport.org

Trigeminal Neuralgia Association

www.tna-uk.org.uk