

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 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 has persistent pain, asthma, prostate cancer and osteoarthritis and has put these tools together with the help of friends, family and healthcare professionals.



Welcome to the Pain Toolkit

- ◆ 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 to understand and manage pain better!

Pete says...

“Living with pain can be tricky, and you may need some help as I did.

Where do you get the help?

Well, you can get help and support from your family, friends, healthcare professionals and



Your 3 step guide how to how best use the Pain Toolkit

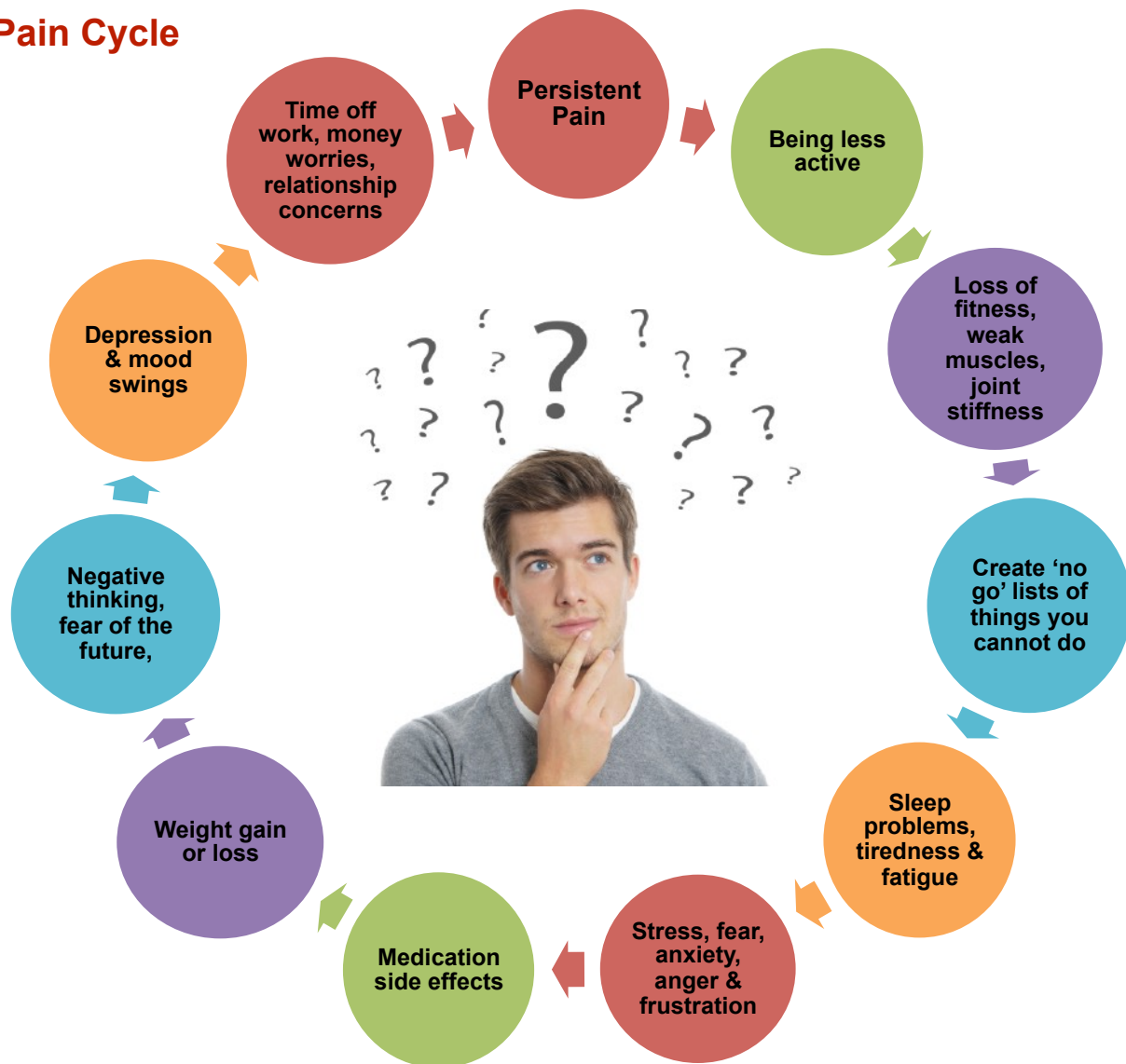
1. Read the Pain Toolkit and show it to your partner, GP/health care professional, friends, family or work colleagues.
2. Tick off or circle the three tools you have the most problems with and show them to your GP/health care professional, friends, family work colleague and ask them for help and support.
3. Once you feel confident with those three tools, then choose another three and repeat the process.

Important tip - using the Red links

Throughout the Pain Toolkit you will see highlighted words in **red** For example here is a good one **Understanding Pain in less than five minutes** These are links to websites, so all you need to do is just click on them.

So, lets get started... and see if you can recognise yourself in the Pain Cycle and answer any of the three questions 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?

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 your family, friends and work colleagues.

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



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.

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

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.

Please remember to discuss with your doctor or healthcare professional before trying a new treatment or procedure.

So is persistent pain a problem in the New Zealand?

The short answer is yes, so you are not on your own. Here are some alarming facts from recent Ministry of Health surveys, about 1 in 4 adults has persistent back or neck pain, and 1 in 6 have arthritis. That's over 1,000,000 New Zealanders with persistent pain.

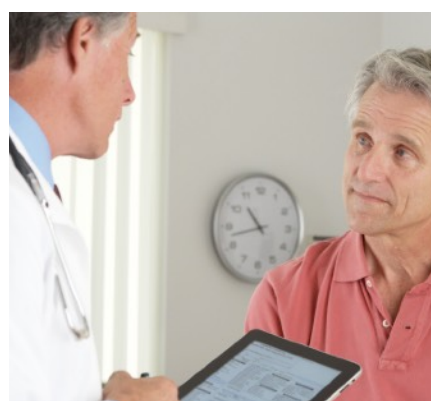


Why do I need to manage my pain? After all I see my health care professional and aren't they supposed to do that for me?

New Zealand Pain Society

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 self-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.

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.

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 better self-manage your pain.



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.

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**? 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. 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.

Boom and bust cycle



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 health care team.



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
- ✦ Relaxation exercises ([free downloadable relaxation techniques](#))
- ✦ Meditation ([Mindfulness](#))
- ✦ Dancing
- ✦ Walking ([Walking for Health](#))



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. 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.

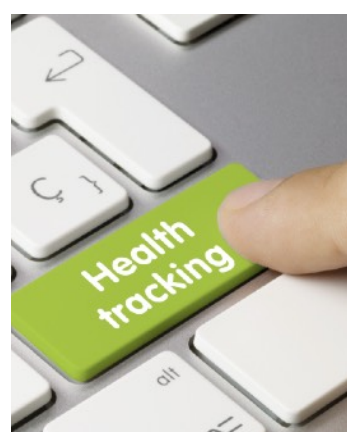


If you are in pain, remember that unfit and under used muscles feel more pain than toned ones. Talk with your physiotherapist or fitness coach about an individually tailored stretching and exercise programme that you can work on steadily and safely. This will help you build your confidence, muscle and 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 16.

Try out the NHS Fitness Studio. Very visual, no membership 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.

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 set-back and what helped.

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

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

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 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?

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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 activities.

Having a setback 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.

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. 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 health care professional for help.

Prioritise your responsibilities.

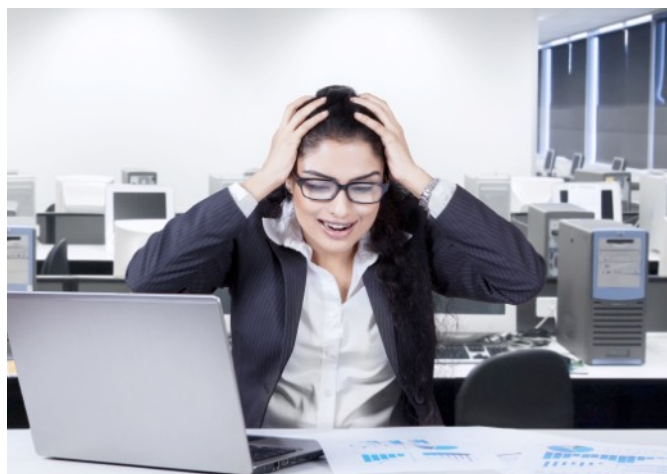
Pace yourself. Break up tasks into smaller portions. Rest in between. Reduce your activities until the set-back settles. Be kind to yourself. Say 'NO' to any unnecessary demands put upon you until you are feeling healthier. And..... don't be too proud or scared to ASK for help!

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!

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 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. Also accept the situation and that you are experiencing a setback, and just as it came, it will go.

Great website **Living with Pain** for free downloadable simple relaxation skills/techniques.



Pain Toolkit in different languages

Yes the Pain Toolkit is in other different languages and they can be downloaded **here**

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
- ✦ Increases natural pain killers (called endorphins) in the bodies nervous system which help control pain
- ✦ Helps with weight control (20 Tips to eat well for less) Also Ask your GP or nurse for a Green Prescription
- ✦ 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



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.

Useful resources and choices to help you

Self-management programmes (SMP's)

These are run in the community by highly trained volunteer tutors who often have a chronic health condition (including pain) themselves but have learnt to become good self managers. Arthritis New Zealand www.arthritis.org.nz run these type of courses. ACC, WiNZ www.workandincome.govt.nz and some DHBs (District Health Boards) www.moh.govt.nz/districthealthboards may also fund or run self-management programmes.



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

Health Talk on Line People's stories: see, hear and read their experiences

NHS Choices is the online 'front door' to the NHS. It is the country's biggest health website and gives all the information you need to make choices about your health.



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) about other local health and community initiatives.

A really useful organisation in New Zealand for advice support living with long term health condition is the Health Navigator www.healthnavigator.org.nz Try also The Ministry of Health site, with links to best treatment information www.moh.govt.nz and www.acc.co.nz Lots of information about preventing and managing injuries , e.g. back pain guidelines, stretches for sports etc.

Making changes and becoming active

Green prescriptions

These are prescriptions for exercise. Your GP can help you get moving by filling out a green prescription (GRx), which is sent to the nearest GRx Patient Support Person who will help you decide on the level and amount of activity, and support your progress.

SPARC (Sport & Recreation New Zealand) is dedicated to getting New Zealanders moving. If you want to know how to start, and what's available to help you anywhere in the country look at their website sparc.org.nz

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**
- ♦ **Exercise Works**
- ♦ **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.

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



Do some relaxation and breathing from the stomach (ask health care professional to show you how to if not sure how to do this diaphragmatic breathing) Exercise, stretching and being active during the day can help.

Depression and anxiety can cause sleep problems, so talk with your GP and ask for help and if necessary see a **Cognitive Behavioural Therapist** (CBT) who has expert skills about sleep problems a self-help manual has more advice regarding sleep and pain management and comes with a special breathing and relaxation CD that many people find helpful with sleep problems.

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.

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.



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 etc. Always discuss with your doctor or health care professional if you are going to try something.

Remember, successful pain self-management is team work.

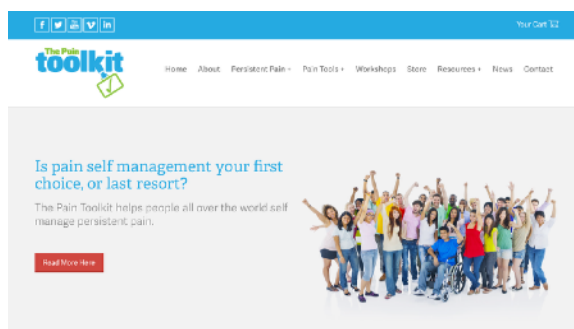


I found the **Health Talk on-line** site very useful. It gave me the opportunity to hear, see and read about how others live with their pain. I now know I'm not on my own. N.K. Somerset.

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

Pain Toolkit website

There is some really useful information on the Pain Toolkit site and yes, its all easy to understand. Many visitors particularly like the **Pain Toolkit videos** as all the information is visual.



Retrain Pain

A **free** on-line course in various languages, to help self-manage your pain.

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 health care 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.



Useful website links for more information and support

ACC www.acc.co.nz Lots of information about preventing and managing injuries

Alcoholics Anonymous
alcoholics-anonymous.org.nz

Angina as a persistent pain
www.angina.org

Arthritis New Zealand
www.arthritis.org.nz

Black Dog Institute
www.blackdoginstitute.org.au
For help with mood disorders.

Burwood Academy of Independent Living
www.burwood.org.nz

Everybody NZ
www.everybody.co.nz

Guided relaxation
www.calm.auckland.ac.nz

Health Information for New Zealanders'
www.everybody.co.nz

Healthtalkonline
www.healthtalkonline.org (peoples experience self-managing with health problems)

Health Navigator NZ – health information for all New Zealanders
www.healthnavigator.org.nz

Health Point www.healthpoint.co.nz
Local information - specialist referral.

Lifeline www.lifeline.org.nz Free counselling service

Mental Health Foundation of New Zealand www.mentalhealth.org.nz

Medsafe www.medsafe.govt.nz
Information about medicines

The Ministry of Health
www.moh.govt.nz

Multiple Sclerosis Society NZ
www.msnz.org.nz

New Zealand Pain Society
www.nzps.org.nz

NHS Choices www.nhs.uk

Pain Concern www.painconcern.org.uk

Pain Relief Foundation
www.painrelieffoundation.org.uk

Parkinson New Zealand
www.parkinsons.org.nz

Pelvic Pain Support Network
www.pelvicpain.org.uk

Samaritans www.samaritans.org.nz

Sleep Foundation
www.sleepfoundation.org

Stroke New Zealand
www.stroke.org.nz

The Lowdown www.thelowdown.co.nz
Helping youth with depression