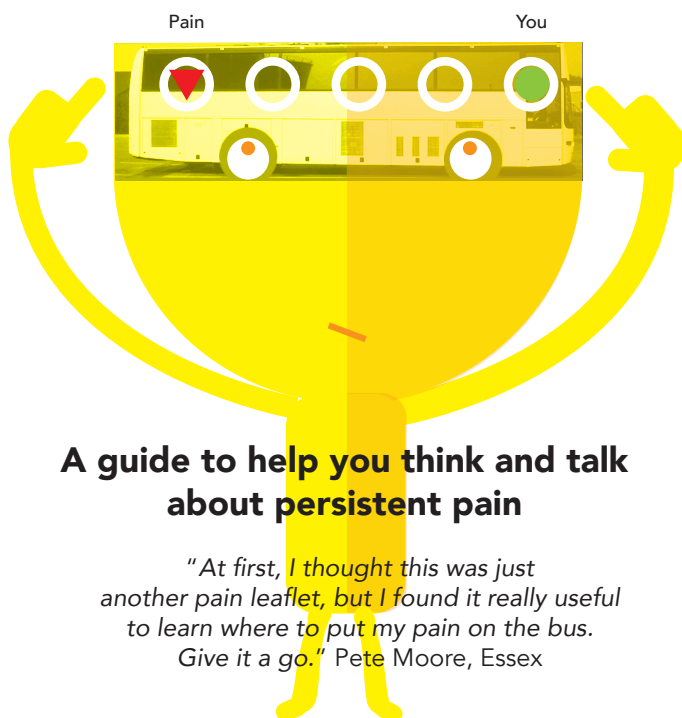


YOUR JOURNEY WITH PAIN



**A guide to help you think and talk
about persistent pain**

*"At first, I thought this was just
another pain leaflet, but I found it really useful
to learn where to put my pain on the bus.
Give it a go." Pete Moore, Essex*

intro

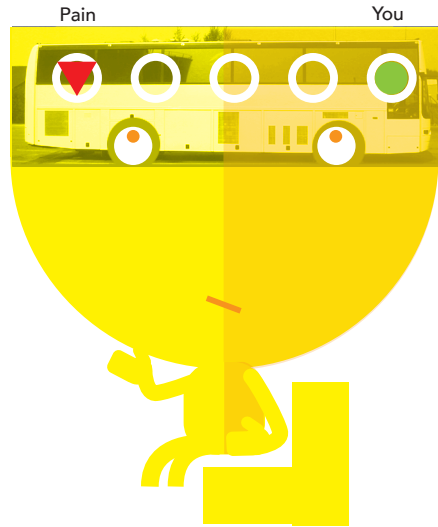
You are the driver of your bus, making decisions and living your life. You choose where to drive your bus. For example, you want to be a supportive friend and keep in touch with the friends you care about. Different passengers travel on your bus. These are your personal thoughts, images, feelings and body sensations - they are private to you. People in your life may influence the different thoughts and feelings on your bus.

One day, pain got on your bus and started to upset you and these passengers. It might feel like you have an unwanted and troublesome passenger on your bus. Pain can make your life and journey really tough. The thing is, you can't throw pain off your bus. So what can you do?

How to use this guide.

It's easy.

Read through it, fill it in and show it to your family, friends and healthcare team. Get them involved.



In this guide we use a green dot to represent you and a red triangle to represent pain. The bus is your journey through life.

Many people with pain struggle to know how to live with pain. This short guide gives you some ideas for how to live a fuller life, despite pain. The ideal way to use this guide is over 3 weeks. First you record the way pain affects you for a week. Next you think of ways to deal with this unwanted passenger. The third week is for recording the impact of your changes.



How long has pain been on your bus?

(Months/Years)

- 1. record the way pain affects you**
- 2. create goals to help**
- 3. record the changes**

who is currently driving?



When pain is driving your bus
you feel...

Less confident to do everyday activities such as housework or going to work.

Like you have to keep up with others.

Like you have to make decisions based only on your pain e.g. not seeing a friend because of a pain setback.

Stressed or out of control.

Fed up.

When you are driving and in control of your bus...

You feel more confident to carry out everyday activities.

You can do more things, more of the time, with others.

You feel more confident to make decisions based what you can do and what you'd like to do, e.g. you can have a good time with a friend despite the pain setback.

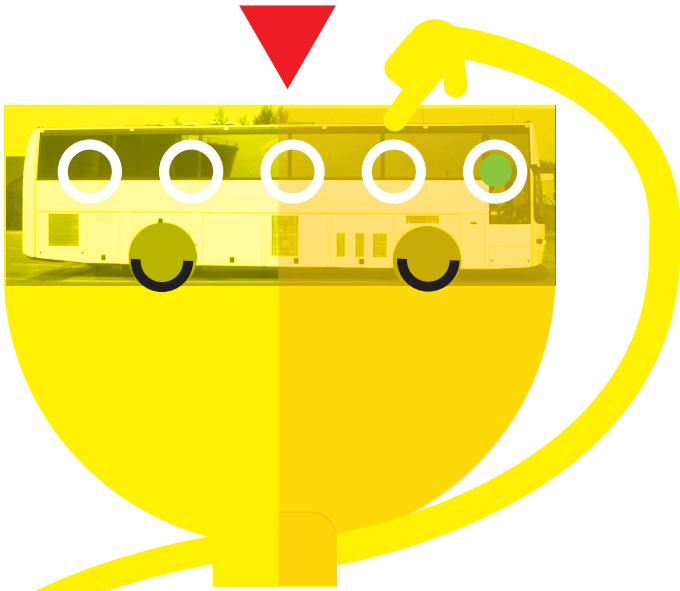
You find ways of managing stress and low mood.

You have hobbies you enjoy.

Tick the boxes that apply to you



where is pain sitting now?



Where is PAIN on your bus right now?
Draw pain as a triangle in the bus seat above.

No ————— | ————— Yes
 Maybe

Is this where you want pain to be?
Put a cross on the line above.

more ideas

and ways to help your journey

Websites to have a look at:

www.paincd.org – useful audio/CD on ways to manage pain

www.painconcern.org.uk – Resources+videos on-self-management.

www.painsense.co.uk – Pain toolkit app.

www.paintoolkit.org – Booklet too.

www.sheffieldpersistentpain.com – Goal setting videos, lots of ideas from people with pain

www.ntw.nhs.uk/pic/selfhelp CBT resources for moods, anxiety, anger, depression, sleep, + MORE

www.breatheworks-mindfulness.co.uk – Invaluable for courses, RESOURCES + CDs, books, etc.

www.stitchlinks.com – Focus on knitting to help manage pain mindfully.

Books to read:

Liiving Beyond your Pain – Using Acceptance and Commitment Therapy to Ease Chronic Pain, J Dahl (2006), New Harbinger.

Overcoming Chronic Pain, Cole et al (2004), Robinson.

Overcoming Sleep Problems, Colin Espie, www.overcoming.-co.uk

The Sleep Book, Guy Meadows, www.orionbooks.co.uk

The Pain Management Plan, R Lewin, Npowered Ltd.

You Are Not Your Pain, Vidayamala Burch and Danny Penman (2015, Flatiron.

The Pain Management Plan, R Lewin, Npowered Ltd.

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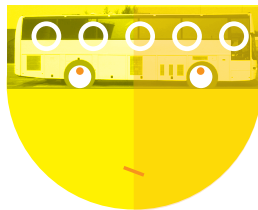
Mark each day where you
and pain are on the bus.



MONDAY	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
TUESDAY	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
WEDNESDAY	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
THURSDAY	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
FRIDAY	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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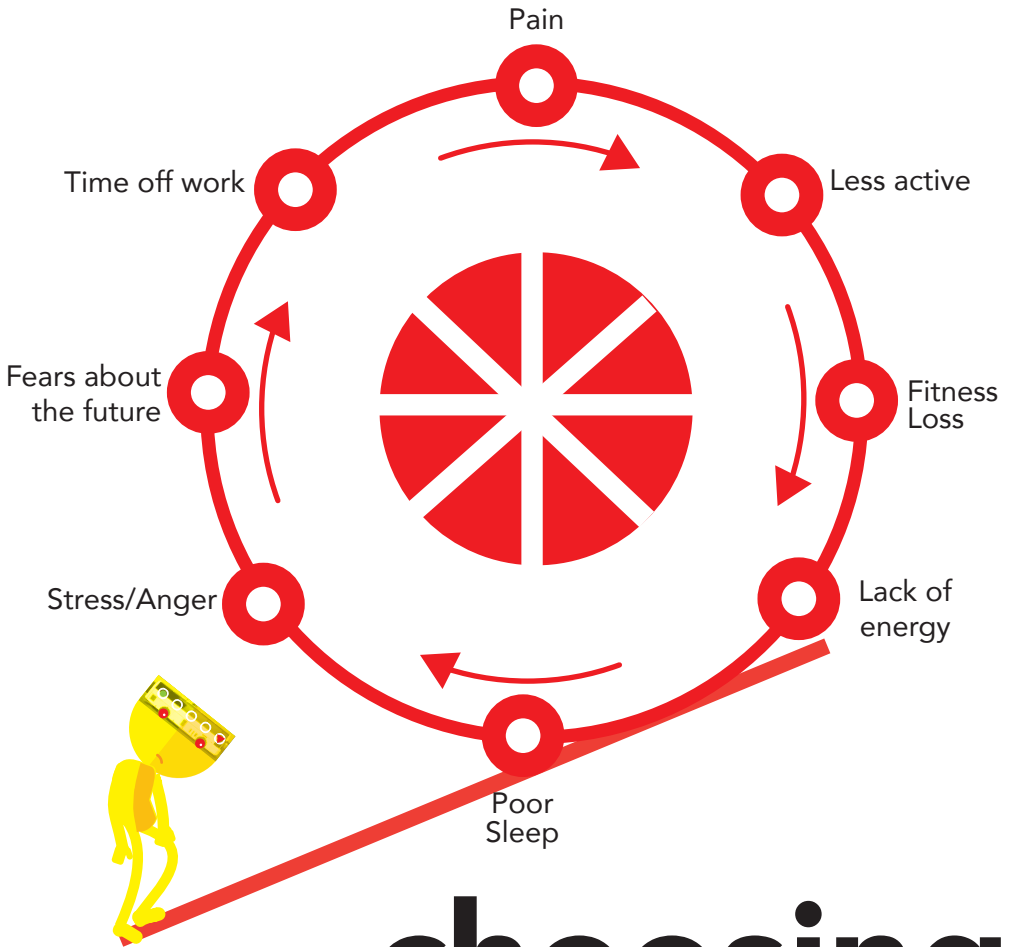
BACK



FRONT

What did you discover this week
about who is driving your bus?
What steps could you take to
help you drive your bus more
often? Put any ideas here:

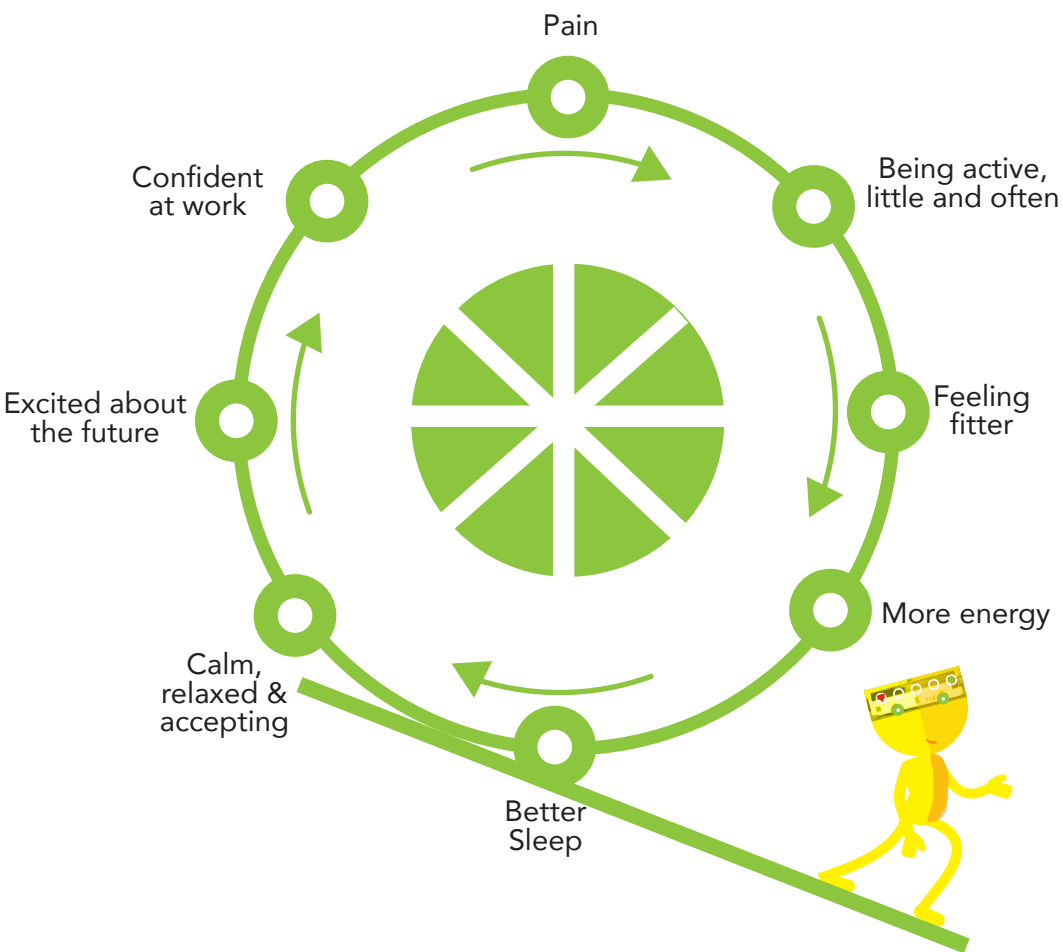
PERSISTENT PAIN WHEEL



choosing

Which set of wheels are you currently driving with?
One set of wheels will help you live more easily with the
pain, the other will make progress more difficult.

PERSISTENT GAIN WHEEL



your
wheels

What steps could you take to become more active? Put any ideas here:

where are you driving to?



We know pain is on our bus and may be there for some time. If pain upsets some of your passengers your thoughts may dictate where you drive e.g. you may think..

“No point going to the park as I can’t chase the kids like I used to.”



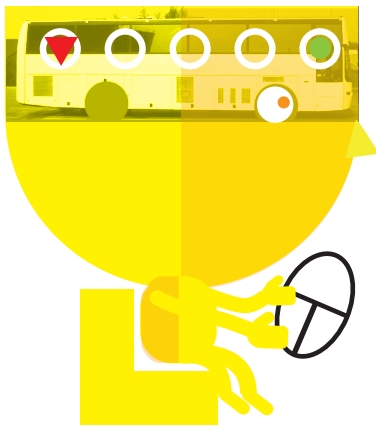
“No point having a coffee with a friend because I’m not good company.”

“I won’t go to the group meeting - I’ll just stay in bed.”

We can’t push passengers off the bus. What we can do is drive the bus to where we want to go, to places that help us live a full life, despite pain.



Think of your life as having positive 'areas' to visit - we've suggested a few bus stops but think of more too.



1. Write down what matters to you under each area. These are the values that you live by and guide the choices you make.
2. Put a circle around the areas you are still happy with despite pain.
3. Underline areas you want to improve. Remember some activities may need to change so you can still do them.

- **Family**
e.g. to be a caring partner

- **Friends**
e.g. to be a supportive friend

- **Work**
e.g. to be a reliable colleague

- **Hobbies**
e.g. to do more things outdoors

- **Health & Wellbeing**
e.g. to prioritise my sleep

- **Education**
e.g. to learn to play the guitar

- **Spirituality**
e.g. to attend a group that matters to me

- **Community**
e.g. to volunteer my help

Record your goals below, even if you only did part of them e.g. googled a local class or downloaded a relaxation app When you didn't achieve what you planned just plan it for another day. Don't be too hard on yourself. Progress isn't always straight forward.



Today I...

Setbacks I had and ideas for managing them

e.g. did some easy garden-
ing outside

e.g. Worried that I'd overdone it.
Will limit to 20 mins each day.

MONDAY

TUESDAY

WEDNESDAY

THURSDAY

FRIDAY

SATURDAY

SUNDAY

Now mark where pain was on
your bus and on the next page.



setting goals



Choose 2 areas from the previous page to set yourself goals in. Try to make them realistic and slowly build them up e.g. start with small walks to the local paper shop, then slowly increase walking distance and time. A goal can be ticked off, so make sure it is a clear plan.

Here are some examples:

Area e.g. family - to be a supportive partner I WILL make time to ask him how his day was while we have tea.

Area e.g. hobbies - to do more things outdoors I WILL take the kids to feed the ducks at the park on Sundays and Fridays.

Area. e.g. Health and Wellbeing - to prioritise my sleep I WILL use relaxation techniques before bed.

AREA

I WILL

Date: / /

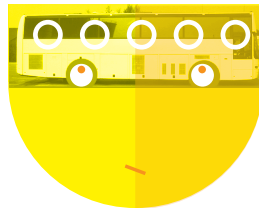
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BACK



FRONT

What did you discover this week
about who is driving your bus?
What steps could you take to
help you drive your bus more
often? Put any ideas here:

week 1



Each day for this week write down the things pain made you do and the activities you did despite pain. Then mark where pain was on your bus on page 6.

Today I...

Today, because of pain, I...

e.g. went for a short walk,
made tea and chatted
with my partner

e.g. didn't phone my friend in
case she asked how I was.
Argued with my partner.

MONDAY

TUESDAY

WEDNESDAY

THURSDAY

FRIDAY

SATURDAY

SUNDAY

Concept & Content: Dr Frances Cole
Content: Sarah Woods
Visual Concepts, Design and Layout: Dr Catherine
Stones

Thanks to Steven Hayes

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