Overcoming agoraphobia A self-help manual

Karina Lovell (1999)

Contents

Section 1

How to use this manual

This manual has been written to help you overcome your problems and should only be used in addition with seeing your therapist on a weekly basis. There are 7 sections of this manual and although most people will want to work through it section by section, each section can be read on its own. In some sections there are exercises for you to do which will help you understand why you have agoraphobia, what keeps the problem going and how to treat it.

It is important to remember that this manual has been written as a general guide and you will need your therapist's help to individualise your treatment with you. The overall aim of the manual is to teach you to become your own therapist.

We have tried to make this manual user-friendly and helpful. We would welcome your comments on the manual, so please let us know what you think.

Section 2

What is agoraphobia?

Agoraphobia is a fear of being in situations from which the person sees that escape may be difficult or embarrassing. A person with agoraphobia may avoid a range of situations, e.g. queues, public transport, large crowded shops, supermarkets, shopping centres. In these situations the person feels anxious with panic feelings (butterflies in the stomach, palpitations i.e. increased heart rate, hyperventilation etc). The person feels that when they panic something 'bad' will happen. These fears are usually about a fear of illness and harm (e.g. having a heart attack, dying, stopping breathing) or a fear of public scrutiny and embarrassment (e.g. falling down and making a fool of oneself).

To help cope with their agoraphobia many people use 'safety behaviours' which help the person to feel less anxious. Such 'safety behaviours' might include things such as being with someone that they trust, being near a hospital or first aid point, carrying something such as an umbrella or a good luck charm of some kind.

Is agoraphobia common?

Agoraphobia is common with 1-3% of the population suffering from it. It is twice as common in women as it is men.

What causes agoraphobia?

There are many different explanations of why people develop agoraphobia. Some believe that there is a genetic link (i.e. inherited) whilst others suggest that life events (such as a bereavement or other traumatic event) may trigger it. It has been suggested that an imbalance of chemicals in the brain cause it. Others argue that agoraphobia is learnt, for example a person has a spontaneous (out of the blue) panic or anxiety attack in a public place and following this they associate panic/anxiety each time they go out. This feeling becomes more crippling and the person learns that avoidance relieves anxiety thus an association develops between going out and panic attacks.

However, no one really knows what causes agoraphobia and for many people it is often difficult to pinpoint to one single cause. Often there are a number of factors, which leads to its development. Many people like to understand why their problems started and your therapist will work with you to try to find a possible explanation. It would be helpful if you could write your own ideas in the box below about why you think the problem started and what are the things that maintain or factors that keep the agoraphobia continuing.

1 What do you think started your agoraphobia?

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2. What are the things that maintain your agoraphobia?

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Why does my agoraphobia continue?

Understanding why agoraphobia continues or is maintained is central to understanding how treatment works. A good starting point is to look at what anxiety is. Anxiety can be seen to have 3 basic components: **physical feelings**, **thoughts** and **behaviour,** which are separate but linked to each other.

Physical feelings – these are the bodily feelings you have when you feel anxious for example palpitations (heart racing) hyperventilating (feeling as though you are having difficulty breathing), butterflies in the stomach, feeling sick, sweating, shaking, trembling.

Thoughts – these are worrying thoughts or images which are often but not always linked to the physical feelings. For example palpitations may lead to the thought "I am going to have a heart attack", or hyperventilating may lead to "I am going to be completely unable to breathe and die". Other people have thoughts which are about embarrassing yourself "I am going to make a fool of myself", and some people fear that they will go mad.

Behaviour - these are our actions or what we do when we are anxious. The most common type of behaviour is avoidance. Other behaviours include escape where someone may try to go into a situation but run away when they feel anxious. Many people will seek some reassurance, such as being accompanied when they go out.

For example Ruth had agoraphobia and avoided leaving home alone for fear of having a panic. She avoided travelling, shopping, and visiting friend's etc unless accompanied by her husband or her friend. If we look at her anxiety using the three parts described above (physical feelings, thoughts and behaviour) we can see how they are linked.

- Physical feelings- "my heart races (palpitations) I get all hot and sweaty, my breathing gets faster (hyperventilation), my legs feel like jelly, and my head pounds.

- Thoughts- "if I go out alone I become panicky and my heart starts beating fast (palpitations) and then I think I am going to have to a heart attack and die".

- Behaviour – "I don't go to crowded places on my own at all (avoidance) and can go to the local shops if I am with my friend or husband (reassurance). I know it is silly but I always carry a few of my tablets (safety behaviour) in case I have a panic. I have tried to go into situations a few times but have always felt so bad that I have had to leave" (escape).

Try to fill in the three parts of anxiety that you feel when you are anxious in the space below.

Physical feelings

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Thoughts

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Behaviour

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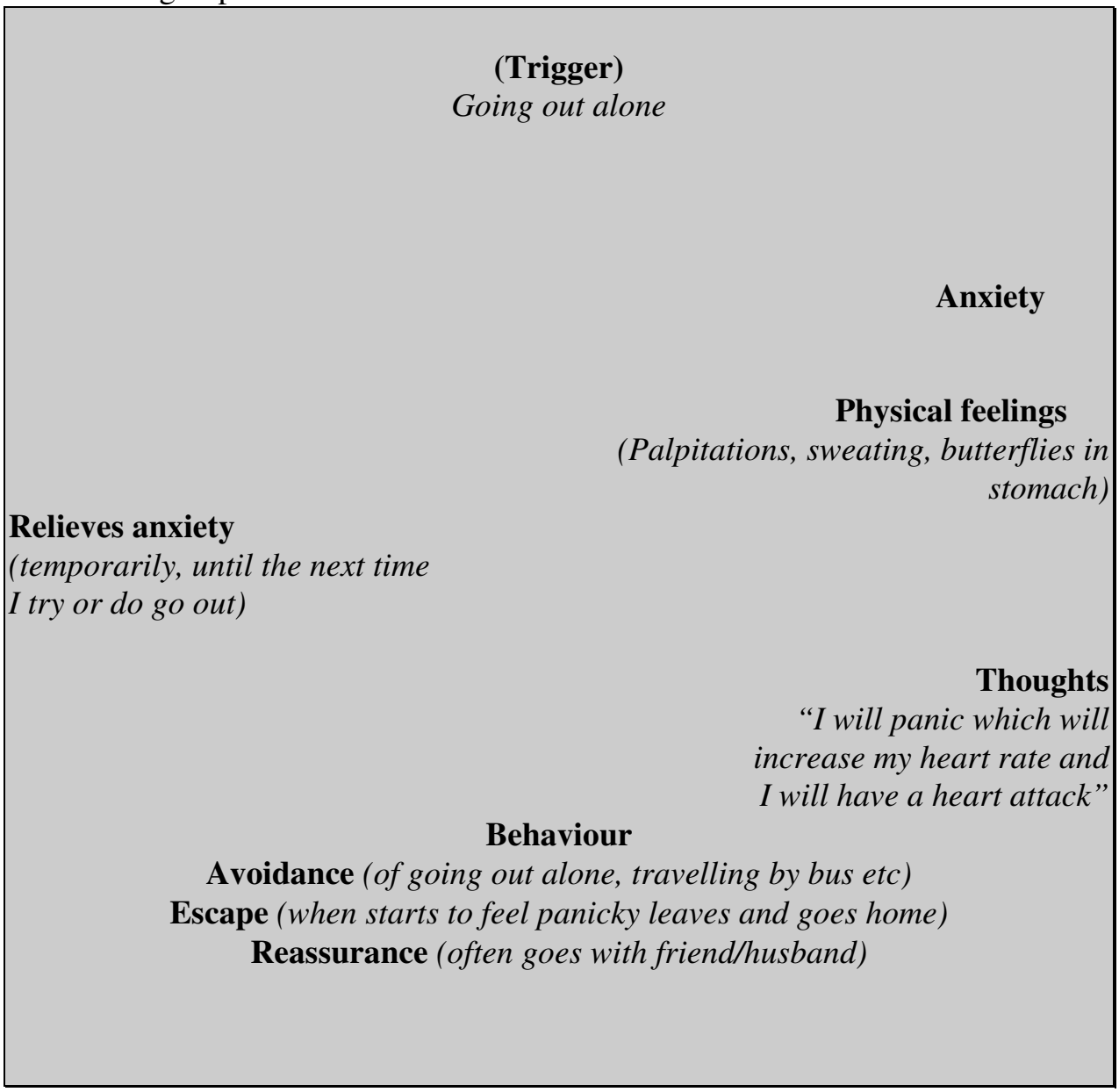
If you have difficulty with this section ask your therapist to help you when you next see them.

Although all three of these parts are important we believe that it is the behaviour (avoiding going out) which maintains or keeps agoraphobia continuing. This will be explained in more detail. For example Ruth's anxiety is triggered when she goes out or even when she thinks of going out. She has physical feelings (palpitations, sweating, and hyperventilation); with frightening thoughts such as "I will have a heart attack and die". Ruth thinks it is better to stay in (she avoids going out) which relieves her anxiety ***BUT*** the relief is only short-term because the next time she tries to go out the same thing happens.

As can be seen in the diagram below a 'vicious circle' is formed and this circle maintains agoraphobia.



In the space below try to complete your own 'vicious circle'. If you find this difficult your therapist will help you.

Triggers

Physical symptoms

Relieves anxiety (temporarily) until the next time

Thoughts

Behaviour

To overcome agoraphobia this circle needs to be broken. In the space below write where you think this circle could be broken and how. You therapist will help you if you get stuck.

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The ‘vicious circle’ can be broken at the behaviour (avoidance and escape). Section 3 explains how this can be done.

Section 3

How to overcome agoraphobia?

Overcoming agoraphobia is possible. The treatment is called ***exposure***.
Exposure means gradually facing your fear until anxiety falls.
We will explain this in more detail. As described in Section 2 avoiding or escaping from feared situations reduces the level of anxiety or panic but only in the short term.

Write down what you think would happen if you stayed in the situation?
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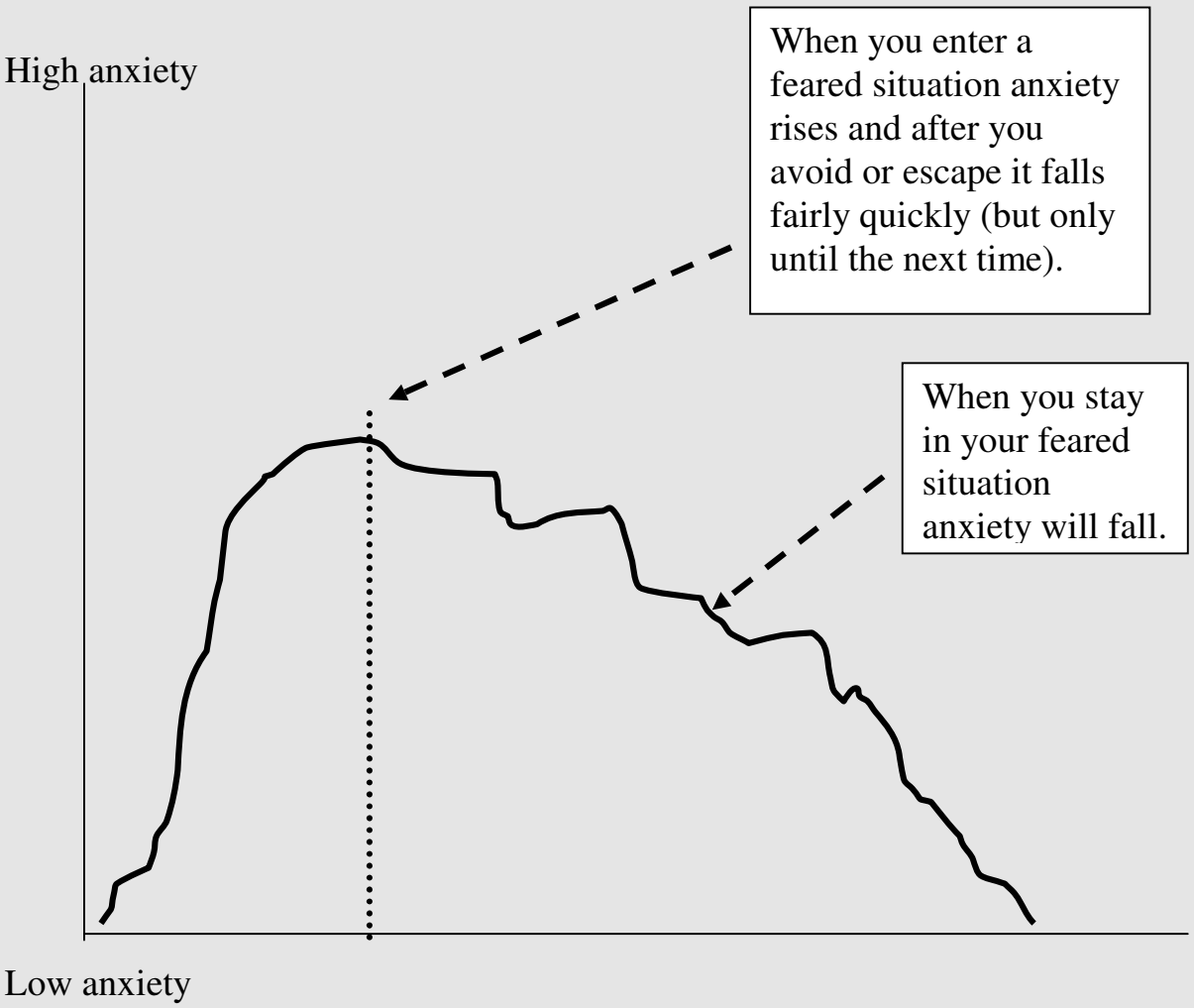
By staying in the situation your anxiety will fall. The following diagram may help you to understand how this works. When we are afraid of a situation like going out we will often try to avoid it. Avoidance does relieve anxiety but only in the short term. Avoidance can often lead to long term difficulties because the vicious circle of anxiety and avoidance build up. Exposure is useful to break this cycle. It teaches you to slowly face the feared situation until anxiety falls.

How exposure therapy works



Whilst facing your fear may sound hard it is not impossible. Try to think of an example in your life where you have felt very anxious about something and after practice your anxiety is reduced. A common example is when we learn to drive. To begin with the learner driver may practise at an airfield or on quiet roads, whilst others start with a driving instructor with dual controls. With **repeated** practise the learner driver becomes more confidant, tackling more difficult situations such as a three-point turn, reversing round a corner, and an emergency stop. If the learner driver only practised for a minute at a time then it would take a long time to become confident, which is why lessons last for 1 hour (**prolonged**). After regular and repeated practise the driver's confidence increases. They begin to feel more comfortable on busy roads, traffic light, and roundabouts.

In the space below try to think of an example when you have felt anxious but after practising you have found it easier to do.

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There are 3 golden rules of exposure therapy (shown in the above example). The first is that it is **graded** which means that you slowly face your fears, starting with something that is easy and building up to harder situations. The second rule is that you need to practise the same situation **repeatedly** (over and over again) until you feel less anxious. The third rule is you should stay in the feared situation (**prolonged**) until your anxiety falls (usually takes between 30-60 minutes).

The three golden rules of exposure

- ***Graded*** **– Gradually facing your fears, starting with something easier and gradually building up to more difficult situations.**
- ***Repeated*** **– Exposure must be repeated, it is important that you practise facing your feared situations many times until you feel comfortable in that situation.**
- ***Prolonged*** **– Stay in the situation long enough for your anxiety to fall by at least 50%, which usually takes between 30 and 60 minutes.**

Although exposure therapy sounds difficult it is not impossible. It is useful to think of therapy in the following way – ***At present you are getting short-term relief by escaping and avoiding your fears but this is not a long-term solution. Exposure therapy will provoke short-term anxiety but lasting relief.***

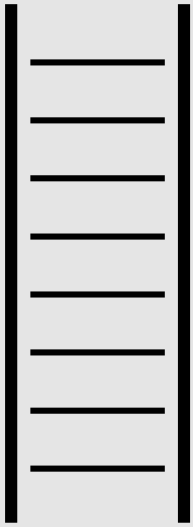
Setting up your own individual exposure programme

With your therapist you will have decided on your end of treatment goals and set up your own exposure programme to help you achieve these. With your therapist you will break these goals down into smaller steps and set ***weekly targets***.

Each week, you and your therapist will agree targets to practice everyday (for example, going to the local shop once daily to buy a newspaper). These targets need to be achievable, though always causing some anxiety. Remember that you need to make steady but gradual progress, so start off slowly. A good way of doing this is to make a list of fears starting with the easiest. It is easiest to think of this as climbing a ladder, start on the first rung and find your footing before your go to the next rung. For example, someone who fears going out and travelling by public transport might have a list like this:

Easiest -

Going to the local shop alone (accompanied)
Going to the local shop (alone)
Going by bus (accompanied)
Going by bus (alone)
Going to the local park (accompanied)
Going to the local park (alone)
Going to the supermarket (accompanied)
Going to the supermarket (alone)
Going to the local town (accompanied)
Going to the local town (alone)
Going to the shopping centre (accompanied)
Going to the shopping centre (alone)
Going by train (accompanied)
Going by train (alone)



Hardest-

In the following space make your own list (if you find this difficult there are examples in the case studies or discuss it with your therapist).

Easiest -

1. ……
2. ……
3. ……
4. ……..
5. ……
6. ……
7. ……
8. ……
9. ……
10. ……
11. ……
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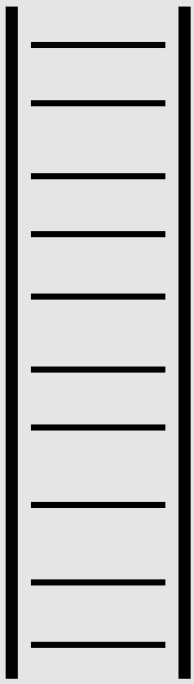
17. ……



Hardest-

Setting achievable weekly targets need to be carefully thought out. Your targets should relate to your list, in our earlier example the weekly targets might be as follows:

Week 1 Go to the local shops with my friend every day for at least 1 hour (for 4 days) then alone for following 3 days.

Week 2 Go on a bus journey for at least an hour accompanied by my friend (for 4 days) and try alone for the following 3 days.

and so on until you have completed all the situations that make you anxious.

A homework diary (these can be found at the back of the manual) is used to write down and record your targets. Your therapist will explain how to complete the forms.

The role of a co-therapist

Many people find it helpful to have support from a relative or friend. To help you they need to understand exposure therapy. If you have a co-therapist it is a good idea to ask him/her to read the manual (your therapist has copies, which do not contain personalised details). Although a co-therapist is not necessary to treatment they often help, particularly in the early stages of treatment. Your therapist will be happy to talk to your co-therapist if you wish them too.

Section 4

Help

This section is to help you with some of the common difficulties in treatment. However if you feel that you want more help ask your therapist.

I don't know how to cope with the anxiety when facing my frightening situations?

This is a common difficulty and there are a number of ways of coping with your anxiety. One way is to use coping statements, these are phrases that that you can say to yourself or write down on a piece of card (often writing them down for the first few weeks is helpful and then try saying them to yourself). For example they may include things like:
"Anxiety is unpleasant but it won't harm me"
"Although I feel anxious now I will feel better in the long-term (rather than what I have been doing which is getting short-term relief but long-term difficulties)".
"The physical symptoms of anxiety are similar to those when I am excited, it is the worrying thoughts that make me feel afraid".
"These feelings will pass"
"I am not going to die"

These are only a few examples, and there are many more that you could come up with. In the space below write down 3 coping statements that you think may be helpful for you. If this is hard ask your therapist to help you.

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Another way to help cope with anxiety is through controlling your breathing. Your therapist can teach you how to do this.

My partner/friend does not know what to say when I ask them for reassurance

Often friends and family have got into the habit of giving reassurance. You need to talk about the treatment to the person who is giving reassurance (or give them a manual to read). As refusing reassurance may lead to arguments we would recommend that if you ask the person for reassurance they should answer "your therapist has asked me not to answer that question"

I have managed to get so far but I just cannot face the next step on my list

It is quite usual to get 'stuck' at some point in therapy. Often the reason for this is that the gap between the stages on the list is too big. This is a common problem and can be overcome by breaking the stages down into smaller parts. For example a person with a fear of using public transport will often manage the first step of going on a bus accompanied but will find the next step on the list of going on a bus alone too difficult. There are a number of ways to break this down i.e. getting your co-therapist to meet you at the bus stop, having your co-therapist to drive behind the bus eventually doing this without support. If you are 'stuck' and unable to find ways around the difficulty ask your therapist to help you.

I am much better now and I want to stop taking my antidepressants - should I?
This very much depends on how your mood has been. It is recommended that you should remain on them for at least 6 months after your depression has lifted. You should not reduce them without discussing the advantages and disadvantages with either your therapist or GP.

I have practised one particular task over and over again and the anxiety does not seem to be getting any better
There may be a number of reasons for this but the most common is that the person is continuing to avoid in one way or another. Such avoidance may not be obvious, for example continuing to use a safety signal and it may be that you are so used to doing it you do not recognise it. Firstly, when you do your exposure task monitor yourself carefully (writing it down may also help) to check and see if there are any 'hidden' avoidance's. If you are unable to find out what the problem is your therapist will help you.

I have managed to stop the avoidance, but I still get the thoughts
This is a common problem, our experience is that first the behaviour changes (i.e. going out, using public transport etc) but people continue to have worrying thoughts (such as they may panic). However these thoughts reduce in time as the person gets more and more used to going out.

Will exposure therapy lead to a complete improvement? Research evidence shows that between 60-75% of people treated with exposure therapy makes some

level of improvement. Importantly these gains are long lasting.

Section 5

Relapse prevention - How to prevent agoraphobia returning?

This section is important and we would suggest that you read it before you complete the treatment. There is a lot of evidence that the gains made during treatment will remain. However you need to practise your weekly targets regularly and eventually these will become a normal part of your life.

If you become depressed, or experience a serious life event (such as bereavement, job loss etc.) or have a period of stress then your agoraphobia may recur. If you are prone to depression you should monitor your mood on a monthly basis using the BDI (Beck Depression Inventory). This is a simple form to complete) your therapist will show you how to do this). It is important that you know what to do if you have a serious life event or become depressed. However it is important to remember that agoraphobia does not come back straight away, it usually comes back slowly. If you become depressed you need to be extra vigilant of the early warning signs of agoraphobia i.e. a tendency to avoid situations on a 'bad day'. As mentioned earlier agoraphobia will not return overnight and it takes take time to develop into a major problem. Setbacks can usually be nipped in the bud and setbacks and relapse can often be avoided.

It is useful (particularly for the first year) to monitor yourself to ensure no signs of agoraphobia are recurring. We often suggest that people should keep a weekly diary of their progress. If you have a co-therapist through your treatment it is important that they are aware of the things that can lead to set back.

Your therapist will discuss and develop an individual relapse prevention plan with you. You will also be given an appointment with your therapist at 1,3, and 6 month following treatment where you can talk about your progress and problem solve difficulties that may arise during this period.

Section 6

Case study

Zoe is a 32-year-old woman who is married and has 1 child aged 4 years. Her main difficulty is a fear of panicking in a public place and collapsing.

Her problems started in her early 20's when she had a panic attack on a bus. The next time she tried to go on a bus she felt anxious and came home. She tried a few more times but failed. Since then she avoided all public transport but overcame travelling difficulties by learning to drive (except on motorways). However after the birth of her child 4 years ago Zoe's agoraphobia worsened. She generally felt more anxious and when her child was 6 months old she had a panic attack whilst driving. She rang her husband who picked her up and took her home, but after that avoided driving altogether. Zoe also started to feel anxious in large shopping centres and supermarkets and started to avoid them.

Zoe came for treatment because she was worried that her problem would get so bad that she would not be able to get out of the house. She was also worried that she would not be able to take her child to school. Zoe was depressed with a loss of interest in previously enjoyed activities (such as reading, watching television, and making specialist cakes).

At assessment the above details were gathered and when we talked about thoughts feelings and behaviour Zoe described the following:

Thoughts - "during a panic I think I will collapse and die"

Feelings - "when I feel anxious I feel 'butterflies' in my stomach, heart racing and hot, when I panic these feeling become much worse and intense, and I feel everything closing in on me".

Behaviour - "I avoid all forms of public transport, driving, large shops, supermarkets, shopping centres and queues. If I can I try to avoid going out altogether".

Zoe always found things easier if she was with her friend or husband and that pushing her child's pushchair helped (safety behaviours). The treatment was explained to Zoe and together with the therapist the following problem and goals for treatment were made.

Problem - 'Fear of panicking and then collapsing in places where escape is difficult which results in an avoidance of using public transport, driving, queues, supermarkets, large shops and supermarkets. This problem impairs my home and social life.

Goals
1. To walk (either alone or with my daughter) to the local supermarket 3 times a week and stay for at least one hour.

2. To drive to friends (approx. 30 minutes away) alone or with my daughter 4 times a week

3. To drive to my parents house (using the motorway) once a week.

4. To go to the local shopping centre alone and shop in large stores for 2 hours at least once a week.

5. To travel by train (1 hour each way) alone once every 2 weeks.

After setting the problems and goals Zoe made a list of fears starting with the easiest.

Shopping at the local supermarket (with husband/ friend) when not busy
Shopping at the local supermarket (daughter in the buggy) when not busy
Shopping at the local supermarket (with daughter walking or alone) when not busy
Shopping at the local supermarket (with husband/ friend) when busy
Shopping at the local supermarket (daughter in the buggy) when busy
Shopping at the local supermarket (with daughter walking or alone) when busy
Driving to my friends house (approx. 30 minutes) with my husband/friend
Driving to my friends house (approx. 30 minutes) alone
Shopping at the shopping centre (with husband/ friend) when not busy
Shopping at the shopping centre (daughter in the buggy) when not busy
Shopping at the shopping centre (with daughter walking or alone) when not busy
Shopping at the shopping centre (with husband/ friend) when busy
Shopping at the shopping centre (daughter in the buggy) when busy
Shopping at the shopping centre (with daughter walking or alone) when busy
Driving to an unknown place (approx. 30 minutes) with my husband/friend
Driving to an unknown place (approx. 30 minutes) alone
Driving to my parents via the motorway (approx. 60 minutes) with my husband/friend
Driving to my parents via the motorway (approx. 60 minutes) alone
Driving on the motorway to a place I have not been before (with husband/friend)

Driving on the motorway to a place I have not been before (alone)
Travelling by bus to shopping centre (with husband or friend)
Travelling by bus to shopping centre (alone)
Travelling by bus to a place not visited before (with husband or friend)
Travelling by bus to a place not visited before (alone)
Travelling by train to a fiends (with husband or friend)
Travelling by train to a friends (alone)
Travelling by train to a place not visited before (with husband or friend)
Travelling by train to a place not visited before (alone)

Once the list had been made weekly targets were set. What weekly target/s do you think Zoe should begin with?

Zoe decided that the first thing she would tackle would be getting to the local supermarket, and for the first week her target was:

1. To walk to the local supermarket with a friend or husband and stay for 1 hour every day.

Zoe was asked to keep a record of how much anxiety she felt in this situation with 8 meaning panic and 0 meaning no anxiety. The next week Zoe had achieved this, and as her anxiety had fallen from 6 to 2 in the last 2 days she had done it alone. She was delighted with her progress and the next week started driving to friends but also continued going to the supermarket. Each week she moved up between 1-2 steps on her hierarchy.
But it was not always easy and many times Zoe felt like giving up. It was Zoe's sheer determination and hard work that led to her getting better. She found the anxiety difficult to cope with and wrote coping statements on a piece of card. She also kept her own personal diary of her progress, so that when she felt like giving up she was reminded of the progress that she had made. At the end of treatment Zoe had made very good progress and was able to travel, shop and visit friends. On some days she still felt anxious but persevered. She achieved all her goals. Her depression improved without any other treatment. At 1-year follow-up Zoe had improved on all the gains she had made during treatment and no longer thought of herself as having agoraphobia.

Section 7

End of treatment goals

Goal 1	**pre**	**mid**	**post**	**1mfu**
……	☐	☐	☐	☐

Goal 2	**pre**	**mid**	**post**	**1mfu**
……	☐	☐	☐	☐

Goal 3	**pre**	**mid**	**post**	**1mfu**
……	☐	☐	☐	☐

Goal 4	**pre**	**mid**	**post**	**1mfu**
……	☐	☐	☐	☐

My progress towards achieving each target regularly without difficulty

	0	**2**	**4**	**6**	**8**
Discomfort	None	slight	definite	marked	very severe
Behaviour	complete success	75% success	50% success	25% success	no success

Section 8
Personal diary

Weekly targets

Goal 1…….
Goal 2…….
Goal 3 ……..
Goal 4……..

Use the scale below to rate your anxiety

0----------2----------4----------6----------8
None Mild Moderate Much Extreme

Date	Weekly goals	Anxiety			Comments
		Before	During	After	

Weekly targets

Goal 1…….
Goal 2…….
Goal 3 ……..
Goal 4……..

Use the scale below to rate your anxiety

0----------2----------4----------6----------8
None Mild Moderate Much Extreme

Date	Weekly goals	Anxiety			Comments
		Before	During	After	

Weekly targets

Goal 1…….
Goal 2…….
Goal 3 ……..
Goal 4……..

Use the scale below to rate your anxiety

0----------2----------4----------6----------8
None Mild Moderate Much Extreme

Date	Weekly goals	Anxiety			Comments
		Before	During	After	

Weekly targets

Goal 1…….
Goal 2…….
Goal 3 ……..
Goal 4……..

Use the scale below to rate your anxiety

0----------2----------4----------6----------8
None Mild Moderate Much Extreme

Date	Weekly goals	Anxiety			Comments
		Before	During	After	

Weekly targets

Goal 1…….
Goal 2…….
Goal 3 ……..
Goal 4……..

Use the scale below to rate your anxiety

0----------2----------4----------6----------8
None Mild Moderate Much Extreme

Date	Weekly goals	Anxiety			Comments
		Before	During	After	

Weekly targets

Goal 1…….
Goal 2…….
Goal 3 ……..
Goal 4……..

Use the scale below to rate your anxiety

0----------2----------4----------6----------8
None Mild Moderate Much Extreme

Date	Weekly goals	Anxiety			Comments
		Before	During	After	

Weekly targets

Goal 1…….
Goal 2…….
Goal 3 ……..
Goal 4……..

Use the scale below to rate your anxiety

0----------2----------4----------6----------8
None Mild Moderate Much Extreme

Date	Weekly goals	Anxiety			Comments
		Before	During	After	

Weekly targets

Goal 1…….
Goal 2…….
Goal 3 ……..
Goal 4……..

Use the scale below to rate your anxiety

0----------2----------4----------6----------8
None Mild Moderate Much Extreme

Date	Weekly goals	Anxiety			Comments
		Before	During	After	