Expert Patients Programme

Patient journeys
A word from the Chairman of NHS Kirklees

This booklet is designed to spread the word about the many successes of our Expert Patients Programme.

The real stories told in these few pages offer very personal accounts of how much patients, and indeed their carers, can benefit from the programme. They are all success stories, showing how individuals suffering from a wide range of long term conditions can dramatically improve the quality of their lives.

The eight week course is all about helping to build confidence and participants are offered a toolkit of techniques to help them manage their illnesses. Just leaf through the patient journeys described here, and you will see that not only have patients been helped to cope with their own lives more successfully, but many have remained involved and are now passing on their new skills and expertise to others.

That’s why I’m a great supporter of the Expert Patients Programme. I hope that GPs, nurses and indeed all health professionals will see the programme as a key element in their treatment of patients with long term conditions.

Rob Napier
Chairman

They are all success stories, showing how individuals suffering from a wide range of long term conditions can dramatically improve the quality of their lives.
My name is Carol and I would like to tell you what the Expert Patient Programme did for me.

I had back problems for more than 25 years but had always managed my condition myself until Christmas 2003 when things went severely wrong.

I was diagnosed with multiple disc degeneration which basically means the discs in my lower back were severely damaged. I had constant severe pain in my lower back and legs and could not function properly at all. I became very dependant on my family at this time and this made me very depressed because I had always been a very independent person. I had to give up work and basically I thought I was finished.

The nurse at my pain clinic suggested I try the Expert Patient Programme for people with long term chronic illnesses, and to be honest I thought it would be a load of baloney to put it mildly. How wrong I was.

The six week programme is given by tutors who themselves are people with long term chronic medical problems. They understand what you are going through. Even though everybody can have different medical conditions most of the problems we face are common to everyone.

I met some wonderful people on the course and it quite honestly changed my life. The course teaches you new skills to combat the problems you face and to help you self manage your condition. After the six week course you are not abandoned, a monthly support group runs for everyone who has completed the course and I can assure you that we have some great laughs (most important), guest speakers on a variety of subjects, and, most importantly you keep in touch with like minded people.

The Expert Patients Programme team, who are the brains and the power behind the programme are absolutely brilliant and we could not do without their sterling work and efforts and friendship.

I found the course so rewarding and made some very good friends who I keep in touch with every week for a coffee and a chat and for a laugh.

I cannot emphasize enough the good work that the EPP does and you will gain invaluable tools and management skills to help you cope with your problems.
Katrina Dali

I can’t remember where I found out about the Expert Patients Programme, but I’m glad I did!

I have met people with similar and different conditions but found out that some problems I have in daily life are the same for all of us. The Expert Patients Programme has helped me to plan and live a healthier lifestyle while living with my conditions.

I have joined other Expert Patients Programme activities to that I can help others who suffer like me and because they benefit me and my family. I have also met some new people and would like to keep in touch with them.

Attending the Expert Patients Programme has given me confidence and motivation. I also enjoyed the education sessions and found them helpful. Even when I was still attending the course I was telling other people about the benefits of the programme.

Whoever had the idea in the first place should be recognised as it has helped a lot of people including myself.

Julia Anderton

I read about the Expert Patients Programme in my local newspaper and thought it might help me to cope with my arthritis and depression.

I attended an evening course Huddersfield - since attending the course I have got a lot of my confidence back and I am now doing some voluntary work.

I would recommend the course to other people who are living with a long term health condition.
My introduction to the Expert Patients Programme

I was at a health meeting through the Patient and Public Involvement Forum at Mid Yorkshire NHS Acute Trust when I heard a reference made to the Expert Patients Programme in Leeds.

As I was in a lot of pain and willing to try anything, I followed this up, discovered one in North Kirklees, my home area, had a phone conversation with Marilyn – filled in a form and duly attended one of the first courses to be run locally.

From then I have never looked back. From being a participant, I followed on becoming a volunteer tutor – after a wonderful course at the Ramada Jarvis Hotel on the outskirts of Leeds led by Jim Phillips, the principle trainer of the National Expert Patients Programme.

I co-tutored on a couple of courses to gain the skills I needed to become an accredited tutor. I achieved the accreditation status in 2006 and now I am able to help others who wish to become tutors by having them co-tutor with me.

I enjoy these courses and feel they have a lot to offer to people with long term chronic illnesses. Help, information, encouragement and confidence is given to participants who all gain in several ways from attending. I and other tutors also benefit ourselves from helping others.

Long may these courses continue.

Irene Snaith

Help, information, encouragement and confidence is given to participants.
How I became an Expert Patients Programme Tutor

Some five years ago, Marilyn came to a meeting of the Kirklees Older People’s Network. She gave a talk on the project which really fired my interest. I thought this is just right for me and applied to go and try to become an Expert Patient. It was one of the first organised in North Kirklees. I got so much from attending all six weeks that I thought I would like to help pass on my enthusiasm by training to become a tutor. This was supported by Marilyn and the people delivering the course.

Shortly afterwards a group of us assembled at Brooklands Hotel near Barnsley (apparently famous for its huge Barnsley Chop) and spent four days developing our skills. It was hard work but we were all dedicated and happily we all passed our final test – at over 70 at that time I was very pleased with myself (the oldest person on the course was in her late 80’s – age has no barriers). I am still in touch with one of my younger co-tutors who I met at the time and she lives in Harrogate.

I was very nervous when I did my first tutoring, however my co-tutor was so helpful and so supportive I really enjoyed myself. The people attending the course were so lovely and they helped each other solve their health problems.

It was realised soon after the first few courses had been completed that something was missing therefore an Expert Patients Programme support group was set up. The one I go to meets at the Salvation Army in Batley and it is extremely well organised by Susan Bateman. First we have a healthy free lunch then a different speaker on a wide range of health topics. We meet for a couple of hours over lunchtime on the third Thursday in the month. The group is open to everyone who has attended an Expert Patients Programme and everyone is welcome.

After co-tutoring on a few courses, it was suggested that I be assessed to become an accredited tutor so that I could lead a course, so I agreed. However, on the day of my assessment I was still ill following a really bad reaction to some tablets. Therefore on the day I was not able to perform to my best and did not get through the assessment. I was very disappointed and upset, but like a true Expert Patient, I pulled myself together and decided I was very happy and fulfilled just being a co-tutor and working with really excellent accredited tutors. I feel that at 78 I am appreciated and I am able to help people on the courses get a better quality of life.

My last tutoring role was working with participants at Dewsbury and District Society for the Blind which was a wonderful experience and I am looking forward to more courses – please!!

I got so much from attending all six weeks that I thought I would like to help pass on my enthusiasm by training to become a tutor.
Sunday 6 January 2007 about 12.30pm. This was the date and time I had my heart attack and was admitted into LGI where I had angioplasty and one stent fitted.

Whilst in hospital I was referred to the rehabilitation department at Dewsbury Hospital who in turn referred me to the weekly meetings at Dewsbury Health Centre. These meetings were held over six weeks and had visiting speakers, these being medical, financial and others.

One of these was Marilyn Horton, EPP Leader. At this stage I introduced my wife Joyce to these meetings and both she and I decided that the EPP could possibly be a good thing for us. We attended the pre-course meeting on the 30 April 2008 and completed the full six week course with a very nice scroll at the end.

The course gave me a boost as having the heart attack it had taken away my confidence and left me at a low ebb. I must mention that without my wife's help I would have been in a worse position. She suffers from diabetes, treated with insulin so has her own problems. I can only speak for myself but I think that Joyce also gained some knowledge from the course about how to treat problems.

The tutors, Irene and Doreen, plus John and Susan ran the course very well and we also made some new friends.

Since the course finished, Joyce and I have joined the support group which is held every third Thursday in the month. This is where various speakers come on a wide range of subjects, some serious, others less so and again we meet another group of people in the same situation as us but with various ailments.

Thinking of becoming a tutor, but as yet undecided as Joyce and I have other commitments.

Recommend the Expert Patients Programme? Certainly, it helped us!

Brian Clayton

Recommend the Expert Patients Programme? Certainly, it helped us!
My name is Malcolm Hirst and I would like to explain how the Expert Patients Programme helped me.

I had bronchitis for quite a few years, then I got pneumonia and pleurisy which stopped me smoking straight away. I had smoked up to 30 a day up to then. I had recurring problems of the same nature, then I was told I had COPD and asthma. From about 1998 up to 2006 I was always in and out of hospital with infections and breathing difficulties. With living on my own I just sat and watched TV getting depressed and not eating properly.

Whilst I was in hospital, Nikki Rochnia from the respiratory unit asked me if I would be interested in taking part in the pulmonary rehab programme – I said yes. The first I went on was at Cleckheaton Health Centre and I couldn’t believe how great the people were who came to it. Some people there were a lot worse off than me. After the course finished, I felt a thousand times better. It turned my life around. While on the course Nikki asked me if I would like to become a Tutor – I said yes I would if I could help people who had problems like myself. I also joined the 10 week Get Food Wise and Exercise Programme to help me with my eating and fitness levels which I completed.

In October 2007 I went on a four day tutor training course in Wakefield with Susan and Jennifer (our respiratory nurse) to learn how to become a tutor – and I passed!

A few days after completing the tutor training course I started to shadow tutors on the COPD courses and then eventually I started to co-tutor on the courses with Jennifer. I have successfully passed on assessment and I am hoping to become a fully fledged tutor on the Expert Patients Programme.

I would also like to thank Jennifer, Susan, Julie and Marilyn for all the encouragement and help they have given me not forgetting Gill who ran the Get Food Wise and Exercise Programme.

I think one of the biggest influences that the Expert Patients Programme has had on me as a person and as a tutor are the people who come on the courses as they actually teach me so much.
My name is Hanifa and I would like to tell my story about being a member of the Expert Patients Programme.

I have attended two courses – one for my long term health condition which is arthritis and one Looking After Me course because I am a carer as well. This is important because I can look after others if I look after myself first. My health helps me to look after someone else.

I have had arthritis now for over five years. It started off as a mild form in my hip joints, but now it affects my hands, feet and knee joints. The pain can be excruciating sometimes. My right hand is affected seriously and I find it very difficult to carry objects. Cooking, lifting heavy pans and the worst part is opening jars etc which are hard even with gadgets.

I found out about the Expert Patients Programme through the drop in centre at Birkby Croft South Asian Healthy Living Partnership. This was all new to me as I have only been going to the centre for just over a year. I was able to participate and meet other people with long term conditions.

The two six week courses I have attended have not made any difference to my health condition, but they have made me aware that I am not the only one, it is not the end of the world and I can still enjoy my life by managing my time and life style, taking things as part of coping.

Now I use my knowledge I have gained to the best and surprisingly I find myself passing it on to friends and relatives who have medical conditions restricting their life style. This has given me further confidence and I feel the best thing I did was to attend the EPP courses and share my views and opinions and meet helpful people. Now I have a good circle of friends and socialise more.

Now I feel like a new, and surprisingly, younger person. I carry on with routines, classes and activities without thinking about my problems and also depend less on medication.

The EPP has certainly been the best thing I have done and I would highly recommend it to all who feel life is boring and that having a long term medical condition is a barrier to a fulfilling life. Certainly not!
“Looking After Me” course

I would just like to feedback to you that I have found this six week course very enjoyable and useful, and I have got a lot out of it.

At first, I was apprehensive about attending, because I would have to explain the circumstances of why I am now caring for my husband. It is only 16 months since it happened and, because it was so sudden and has turned our whole lives upside down, all my emotions are still very raw, and I knew I would find it difficult to talk to others about it.

However, once that was out of the way at the first class, I felt very comfortable with everyone in the group and have looked forward to coming each Wednesday morning. Indeed I have found it to be uplifting and beneficial and I will miss it a lot when it finishes today, and I am very pleased that I will be able to follow it up by joining the new Looking After Me support group.

The content of the course has been excellent, and I think it struck a good mix and balance of information and practical help. The relaxation and cognitive exercises have been particularly helpful for me, and have given me something concrete to take away with me.

The tutors, Laura and Melissa, have shown great empathy and run the course in a sensitive manner and my fellow carers have all been lovely, warm people.

The three aspects of the course I have personally found most helpful were:

- The relief I got from being able to talk with others in the same position. Whatever their circumstances and situations, being carers, they all experience the same emotions, concerns and problems, so this makes one feel less isolated.
- The fact that you can share as much or a little as you want with others, either in pair work (which is very therapeutic) or with the group as a whole, and that is all completely non-judgemental.
- That it actually gives you permission to think and care about yourself, without feeling guilty, which is liberating.

We were asked at one meeting if any of us would like to train as tutors. I would be very interested in doing so, further down the line, when my own life and situation have become more settled and on a more even keel.

Having formerly been the community development and volunteering manager for Age Concern Bradford and District for 11 years, it is very much my field of work. I have a great deal of experience in facilitating groups and running seminars etc through my work in the voluntary sector, and I am sure I would really enjoy being a tutor. Therefore, I will certainly bear this in mind for the future.

In conclusion, I would like to thank you very much for running the Looking After Me course, it was just what I needed. I will definitely spread the word and recommend it to others.

Sue Booth
Darren Devonport

My name is Darren and I suffer with two long term medical conditions – one is ulcerative colitis and the other is diabetes. Living with ulcerative colitis is difficult, uncomfortable and painful and I control my type 2 diabetes with tablets.

I found out about the Expert Patients Programme at the carers group meeting at Birstall Methodist Church when Marilyn came to talk to the group about the courses. I followed it up – made new friends and never regretted it.

The Expert Patients Programme has taught me how to cope with my conditions – I also attend the support group meetings.

Shanaz

My name is Shanaz and I have diabetes, high blood pressure, depression, asthma and breathing problems. I feel very lonely most of the time and worry a lot. Living with so many health conditions makes me feel awful.

I found out about the Expert Patients Programme from my health trainer who suggested that I attended one of the courses which I did.

Because of the course I have made some new friends. I have listened to, and talked to other people about their illnesses and realised that there are other people just like me who are living with a lot of health problems. The people on the course were very friendly and I was happy for six weeks. I would like to join in with more events
Welcome to my world

Hello, my name is David. I am 60 years old and remember too many changes, good or bad, but to health matters in my case only good.

About four years ago I suffered two strokes, had two bouts of pneumonia (thank goodness for spell check) and was hospitalised for some 16 weeks.

Returning home was a daunting experience but overcome, then started the long road to recovery helped by various organisations and hindered by more than the norm. And then EPP was introduced to me and my limited lifestyle started again.

The first meeting led to the course being cancelled as only two people turned up (we could not possible eat all that food!)

The second attempt was met with more than enough doubt but I went again to an induction night. Meeting lots of people who are either worse off than me or just plain scared. Being able to share experiences and able to identify my fears as others have the same.

The course lasted six weeks, being asked to attend at least four weeks. During this time we were given an action plan and asked to attempt to do an activity not undertaken before. Then a week later, as a group we explained what was achieved and identify any problems encountered again talking through them.

Everyone involved in this work, from setting up and delivering the course material have first hand knowledge of most of the conditions encountered but are not allowed to give any medical advice and will point any queries to be addressed by your own GP.

Assorted course material as part of the programme was given out but what I got out of the time I spent with other people was just that you are not alone.

Following the course I thought about volunteering to become a tutor – I attended and successfully completed a four day tutor training course in Sheffield in October 2008 and I passed!

The next step for me is to sit in on some courses so that I can gain the skills and experience and learn from established tutors about delivering the course sessions.

I am about to embark on the next phase of my Expert Patients Programme journey!
My name is Satwant and I would like to tell you about the Expert Patients Programme.

In 1985 my young brother was killed in a plane crash – the plane was blown up over the sea and 460 people died including my brother. In 1989 my son died at 17 years old with a brain tumour. He was a smart intelligent boy. Because of these horrible things happening I became ill and depressed.

However, I later attended the technical college and the Ray Street Enterprise Centre which was good for me. I made lots of friends and my social life started again. I joined a gym and started exercising which has helped with my weight loss, my blood pressure and cholesterol levels.

In 2006 I found out about the Expert Patients Programme and joined a course which was held at Birkby Croft in Huddersfield. I attended for six weeks and was awarded a certificate for completing the course.

In the summer of 2007 I found out about the Looking After Me course for carers – as I am also a carer I joined the programme because I thought it would help me. The course was held at the South Asian Healthy Living Centre at the end of 2007. I feel much better since attending the course – I am more active now and have made some new friends who are carers like me.

I joined the Get Food Wise and Exercise Programme at the Mission in Huddersfield and also joined the Support Group which meets every month. I have also joined in with the different health events and photo shoots.

I have reduced my weight, my blood pressure and cholesterol levels have come down as well and I feel much better now. I have also started walking since taking part in the programme. I really enjoyed the courses and made more new friends. I have started a daily walking group – we walk for 35 minutes every day – so my health is very good now – if your health is good you feel much better.
When I found out about the Expert Patients Programme I was having a lot of personal difficulties and was suffering with depression and I had just found out I was pregnant.

I just managed to complete the course before the baby was born. I was not able to join in much afterwards, but I have since been back in touch with the EPP team who have been excellent and have helped me a lot.

All the information and help from the doctors and the NHS has been great. I have joined PALS which is brilliant and I also have joined in with some of the health events and have joined the support group in Batley.

I feel a lot better now and would recommend anyone to join the Expert Patients Programme – I feel a lot better and more confident now.

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Looking After me course for carers

If you fancy to perk yourself up, you really have no further to look

A simple course that’s friendly and free, it’s called just “Looking After Me”

You will make new friends and feel much better,
learn quite a few tips, maybe write that letter
So if you get the chance to go, do it, you’ve nothing to lose, don’t be slow!
A message from a former carer

I was a carer with 25 years experience in that role, as a result of which I suffered both physically and financially.

When my caring role finished I felt somewhat isolated. Fortunately, I stayed sound emotionally and enrolled on college courses which benefited me enormously and I felt like a real person again.

I did however feel as though I wanted to help others and share my caring experiences. I saw an advertisement for an Expert Patients Programme, decided to investigate, and enrolled on the course. One of the best decisions I have ever made.

I was made welcome by everyone at Gateway to Care and made friends on the course. We shared our problems and had expert tutors, Laura and Jo. We had an excellent lunch provided, tasty and healthy sandwiches, including vegetarian, fresh fruit, fruit juice, tea and coffee.

This course has been extremely beneficial with an added bonus of making new friends.

I now attend the support group monthly meetings and through this I have recently completed a first aid course.

I would definitely recommend this course – it will do wonders for you.

Sheila’s poem

Early last year I went to Gateway to Care

I joined an Expert Patients Course and made some new friends there

We discussed our problems and shared our points of view

It’s good to know that others are feeling just like you

We got advice from tutors, their names Laura and Jo

They understood our feelings and stopped us feeling low

So if you’re in this position and not sure what to do

Just come along and join this Course

A decision you’ll not rue!!
Christine

I came to the Looking After Me course after some serious difficult times both as a carer and as the person being cared for.

The course has given me confidence, support and knowledge to tackle even the most difficult of situations. Rather than seeing my situation as a burden or being a burden to my carer, I see it as a choice.

Thank you

Anonymous

Thank you for the Looking After Me course

I joined the Expert Patients Programme Looking After Me course for carers following the death of my mother and it made me realise I was not well myself. The course enabled me to meet people like myself and I was helped and guided along with way. I feel much more in tune with the outside world now. I wish I had known about the course whilst I was a carer because it would have helped me.

Thank you NHS Kirklees for the help I needed. I truly looked forward to my few hours a week and I have put into practice the help and advice I was given on the course.

Rhoda Patricia Bruce’s

When I was asked if I wanted to go on the COPD course I couldn’t wait! However with family problems I had to wait for nine months before I was able to do it.

I came away from the first session feeling a million dollars. The positive way we were treated was wonderful. I had no fear at all and was determined to do everything I was told.

All the experts were fantastic – Susan, John, Pat, Jennifer, Beth, Katie (I hope I haven’t missed anyone out!) were very special and just knew how to get the best out of us all. All the talks we had were great too.

I have now finished my course and hope to meet with fellow members at the Thursday monthly support group.

I just want to thank everyone concerned for making such a difference to my life. I am now going to be a new 75 year old woman.
Anonymous

My brief story of living with emphysema and a helpful and enjoyable solution...

I used to walk to the newsagents every morning for a newspaper, I enjoyed the walk and the little exercise it gave me. Then it happened…I suddenly became short of breath, began coughing, went very dizzy and felt as though I was about to pass out. I sat on a wall until I recovered then slowly made my way home.

An early visit to the doctors resulted in hospital appointments, tests, more tests and being informed that I had emphysema. I was supplied with two or three inhalers to use at various times throughout the day. I smoked cigarettes for more than sixty years and gave up the habit just thirteen months ago wishing every day that I had never started (the thing is, I used to enjoy each smoke).

I had always been active around the house and garden but with the onset of emphysema I suddenly found that any physical effort left me gasping for breath, even using my inhaler. Things like mowing the lawn, which used to take me three quarters of an hour now took and hour and a half or more due to frequent rests. Walking was tiring even on level ground and any task that required even minor effort caused me to be breathless. I used to dread having a shower, after washing and drying I was in a state of virtual collapse and gasping for air.

My consultant recommended that I should go on the pulmonary rehabilitation course and my doctor informed me I had been placed on the waiting list. The programme lasted for eight weeks and I cannot praise the friendly staff and course content highly enough. Exercises are taken at your own pace with the aim of improvement at each session and are usually followed by a discussion or talk on subjects such as:

- Energy conservation
- Exercise
- Diet
- Breathing/breathlessness
- Relaxation
- Pacing activities

I enjoyed the course and felt a lot better for the exercises and for the information given for managing the symptoms and the disease.

I recommend the programme to anyone with COPD. I felt a lot better for it and hope to continue so.

My main aim in life is to keep going…
I currently care for my son who has BPD and general anxiety disorder. My son lives independently and is also under the care of the mental health services. I have IBS and suffer from asthma and depression. I also care for my husband who has a long term heart condition and chronic asthma. He works full-time and I work part-time. The main concern for a carer of someone with a long term illness is the isolation and loneliness of the carer and at times sheer desperation.

I came about the Expert Patients Programme through being referred by the community psychiatric nurse. I have just completed the Looking After Me course for carers at Gateway to Care and found that invaluable as there were like-minded people there, who were also looking after a loved one with a long term illness.

I learnt how to make time for myself and the importance of this time. How crucial it was for the well-being of myself and those I look after. I made lots of new friends and had time out from my caring role, solely for myself without the guilt factor.

I learnt so much from this course that I applied for a place on the Expert Patients Programme course at the Media Centre and was fortunate to be accepted. I am currently in the middle of the course and have found this to be crucial to me as my son has had a crisis and the support and encouragement that has been given to me by the tutors and the other people on the course is second to none. They have all been tremendous in their response to my situation, sharing true compassion and care.

Being a carer is the loneliest job in the world. But having those courses has given me a greater understanding and compassion of what it is like to care for someone.

I am so pleased that I got up the courage to go to both courses as I have gained such a lot and feel so enriched by it that I no longer feel as lonely. I would encourage others to make the effort to go on the courses – to me they are a life line.
Course details

**Expert Patients Programme Course**
A course for anyone with chronic or long term health condition(s) who wants to learn skills for managing and improving their health. Delivered in English or Urdu.

**Expert Patients Programme Course – Asthma**
A course for people living with or caring for someone with Asthma.

**Expert Patients Programme Course – COPD**
A course for individuals living with COPD

**New Beginnings**
A course for individuals living with or in recovery from a mental health condition.

**Looking After Me Course (LAM)**
A course for adults who care for/look after someone living with a long term health condition or disability including mental health problems, someone who is ill, frail or elderly or someone with a drug or alcohol problem. Delivered in English or Urdu.

**Future developments**

**Supporting Parents Programme** – A course for parents, guardians and carers of children who have long term and life limiting conditions.

**Persistent Pain Programme** – A course for people who live with day to day persistent pain.

Other courses in community languages to be developed and delivered across Kirklees.

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**For more information and details of courses:**

**Expert Patients Programme**
Telephone: 01924 351448  
Email: epp@kirklees.nhs.uk  
Or visit www.kirklees.nhs.uk

**Looking After Me**
Telephone: 01484 226050  
Email carers.gateway@kirklees.gov.uk  
Or visit www.expertpatients.co.uk for local details.

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