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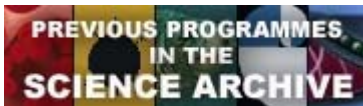
TRISHA MACNAIR

CONTRIBUTORS:

LIAM DONALDSON
JAMES LOCKE
KATE LORIG
JANET COWLARD
DAVID JEWELL
LIZ MCCAULEY
RUTH WHITING
CHARLOTTE JOHNSON

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GERALDINE FITZGERALD**NOT CHECKED AS BROADCAST**

MUSIC - TRACEY CHAPMAN - TALKING 'BOUT A REVOLUTION

MONTAGE

It's very much like a bag of practical tools that you can dip in and dip out of when living with a chronic condition.

The idea that the NHS should be turned into a giant self-help group has some very superficial attractions to it. I can just hear in the back of my mind civil servants rubbing their hands.

MUSIC

Living with a long term condition I've found it - personally it's really changed my life. It definitely helps you regain your confidence.

DONALDSON

Well I suppose you could describe it as a revolution, certainly the idea that patients might be seen as more expert than their doctors in the management of their condition is a pretty radical idea and something that seems to be very widely welcomed.

MUSIC**MACNAIR**

Professor Sir Liam Donaldson, Chief Medical Officer of England and Wales, talking about the NHS Expert Patient Programme or EPP. Today I'll be looking at what the EPP is and how it developed. Next week we'll be finding out whether it lives up to its promises.

Seventeen million people in the UK live with a chronic health problem such as arthritis, diabetes, heart disease or multiple sclerosis. In 2002 the NHS set up a new training programme specifically designed to help people living with chronic conditions to become equal partners with their health professionals, and develop skills which would enable them to take over some of the management of their own illness.

So far 20,000 people have taken part. James Locke is one of the tutors on the EPP in Hammersmith and Fulham.

LOCKE

All of us have dreams in our lives don't we and it's dreams that actually motivate all of us. But you know when you're diagnosed with a chronic condition you feel that all your dreams go out the window and maybe there's nothing left in life for you to live for.

READING - SUSAN SONTAG READ BY ELIZABETH MANSFIELD

Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.

MACNAIR

When, as Susan Sontag suggests, fate deals you a passport to the world of chronic illness, the Expert Patient Programme aims to make the citizenship of that battle-strewn land less arduous.

ACTUALITY - EXPERT PATIENT PROGRAMME

LOCKE

Good morning everybody and a very warm welcome to the first Expert Patients Programme that we're delivering here within Hammersmith and Fulham Primary Care Trust. My name is James Locke and I have been living with HIV infection now for over 21 years. What I would like each and everyone of you to do is to just introduce yourself, give your name and perhaps your condition if you wish and one or two problems that you have living with a long term chronic illness.

PAPA

My name in short is Papa. I suffer with osteoarthritis. My main problem is the knees and I still suffer a bit with sleeping.

PITCHER

My name is Archie Pitcher. I'm a Type II diabetic. I'm 77 years old and I've been diabetic for 25 years.

LOCKE

The chronic disease self-management course is held two and half hours every week, over a six week period. And the items that we look at are action planning, problem solving to enable people to identify their problems and how to go about solving those.

ACTUALITY - EPP

LILIAN

So because of the pain and fatigue, muscle fatigue, it prevents me from being able to actually do any exercises, without increasing my pain.

LOCKE

Okay pain, muscle ...

LILIAN

Fatigue yeah.

LOCKE

Muscle fatigue?

LILIAN

Yeah.

LOCKE

Would anyone here have any solutions, thinking of our problem solving steps that we looked at earlier on, to help Lilian?

[What about massage?]

LOCKE

Massage.

[Acupuncture]

LOCKE

Acupuncture.

[Swimming]

LOCKE

Swimming. Okay there's some good ones there. Lilian, anything there? Have you actually tried them all?

LILIAN

Yeah.

LOCKE
You've tried massage?

LILIAN
Yeah that hurts.

PAPA
I notice Lilian practices different way for finding solution.
How about - did you change any diet?

LILIAN
No.

PAPA
Please do that.

LILIAN
My diet is out of control. I comfort eat unfortunately yeah.

LOCKE
Dealing with difficult emotions, living with a chronic illness, is a bit like being on a roller coaster, you're up and down. So we need to look at practical ways of dealing with those emotions. And looking at something that we call cognitive symptom management.

MACNAIR
Just tell me a tiny bit more about cognitive symptom management - that sounded quite interesting as you referred to that?

LOCKE
Cognitive symptom management really is telling us how powerful the mind is. There are a number of techniques one can use in dealing with chronic illness, so, for example, visualisation techniques, guided imagery, relaxation - these are just to name a few techniques where one uses the mind.

ANN
Well I use distraction technique everyday to get off to sleep and it's great if you wake up in the night and you're in pain, I use letters of the alphabet for different flowers, countries, famous people - go through them - and fortunately by the time I've been through the alphabet twice I've usually dropped off to sleep.

LOCKE

Working with your healthcare team, making treatment decisions, incredibly important that people make informed treatment decisions about their conditions. Living wills and powers of attorney - again important documents that we need to think about from time to time, whether you're ill or well.

MACNAIR

Taking an active role in managing their illness, in partnership with their health professionals, is something that most people aren't very used to. At the start of the EPP in Hammersmith and Fulham, some people on the course seemed quiet - uncertain of what to expect and hesitant about coming forward with ideas and opinions - rather like patients in medical clinics and doctors surgeries around the country. So at the end of the first session how does participant Eleanor think it compares, so far, with her expectations?

ELEANOR

I thought it would be rather like a lot of people sitting around together and talking about their illnesses but so mostly showing you the techniques for managing your situation and symptoms and that makes a lot of difference if you're actually getting something out of it rather than just talking about it.

MACNAIR

So in Fulham at least, initial reaction from participants is favourable. We'll find out next week what their final verdict was, at the end of their EPP.

But how did the idea of training patients to become experts in their own condition come about? In the voluntary sector self-help or support groups have been offering self-management advice for decades. The specific model for the Expert Patient Programme was first developed in California by Kate Lorig, Professor of Medicine at Stanford University. I asked Professor Lorig, who herself has a long term health condition, what the aim of the programme was?

LORIG

The elements of the course are mainly giving people the confidence that they can do things. What happens when you have one or more long term conditions is that very quickly you end up feeling like you can't do anything or what's the use trying. And then at the same time you're getting all these messages - you have to change your diet, you have to change your exercise, you have to do these exercises, you have to do breathing exercises, you have to do this and that - and people just get overwhelmed and they throw up their hands and do nothing. And so what we try to do is help people break things down into very small doable parts and especially things that are important to them.

MACNAIR

Tell me a little bit about when it began and what was the impetus behind it.

LORIG

We had started doing arthritis self-management programmes in the early 1980s and as we worked with people with arthritis they kept saying to us well you're telling us one thing and our cardiologist is telling us another thing, and the more we heard messages like this the more we began to realise that the self-management approach of having a long term condition is really pretty much the same across diseases. And so we applied to our federal government, to our national institutes of health, for funding to try out this notion. The programme at that point was called the Chronic Disease Self-Management Programme and we did a randomised trial of nearly a thousand people to look to see what happens when you put people with various types of long term conditions in one course together. And so that was the genesis of the programme.

MACNAIR

How did it progress, how did this initial trial go - what did you find?

LORIG

What we found was that people changed behaviours, they had improved health status and by that I mean that they had less fatigue, they had less distress about their health, they had less shortness of breath and they also had less utilisation of health resources.

MACNAIR

So this was looking like it was going to be a saving of money - was that the main aim?

LORIG

Well no it actually it wasn't the main aim, the main aim, as far as we were concerned, was that people had better quality of life. If you happen to get cost savings, that's a bonus.

MACNAIR

Even so, the first courses run in the USA were based on the experiences of people with one particular problem - arthritis. And it was Arthritis Care, the voluntary organisation for people with this condition, that introduced the idea of self-management into the UK. One of the first to benefit was Janet Cowlard, now training services manager for Arthritis Care, who was trained by the doyen herself - Kate Lorig - in 1993, after illness had disrupted her life to the point where work as a teacher had become impossible.

COWLARD

I mean before I decided to give up work I was very grumpy at work with the group of children that I was teaching and I felt I did become very reclusive for a while and isolated and thought that I was worthless really because I didn't feel that I was contributing to the household finances, I thought about each hospital appointment and sort of waited for each time I was on a new treatment to hope that it was going to do something for me.

MACNAIR

Participating in the self-management course led to a complete turn around in Janet's life.

COWLARD

I think the main thing is probably my confidence that I've actually gone back to work again and I've been working since I think it was 1997 when I went back to paid employment again and that has done me an awful lot of good. I feel in control of my life, I feel that I'm able to change my condition in some way by using some of these techniques and I feel that I'm back to the person that I was before I had to give up work. I feel that I'm a person first and my condition is secondary to me.

TOLSTOY READING

Doctors came to see her singly and in consultation. Talked much in French, German, and Latin, blamed one another, and prescribed a great variety of medicines for all the diseases known to them. But the simple idea never occurred to any of them that they could not know the disease Natasha was suffering from, as no disease suffered by a live man can be known, for every living person has his own peculiarities and always has his own peculiar, personal, novel, complicated disease, unknown to medicine.

MACNAIR

The idea that people living with an illness know themselves and their own particular condition better than anyone - including their doctors - is one that Tolstoy understood when he wrote War And Peace. It's also something that Liam Donaldson recalls from his days as a medical student.

DONALDSON

I remember years ago as a medical student the consultant turning to me after we'd been in outpatients with a range of people with diabetic illness and he said to me - The patients know more about their disease than we do.

MACNAIR

But although Tolstoy recognised a patient's expertise nearly

140 years ago, and Liam Donaldson's consultant drew attention to it a number of decades ago, most doctors continued to dole out a very paternalistic form of care until remarkably recently. Often Sir Lancelot Spratt in Doctor in the House would feel more like fact than farce:

DOCTOR IN THE HOUSE - SIR LANCELOT SPRATT

Where shall we make the incision? Nothing like large enough. Keyhole surgery - damnable, couldn't see anything, like this. Now don't worry this is nothing whatever to do with you. Now you. When we've cut through the skin what's the first substance we shall find?

Subcutaneous fat sir.

Quite right. And then we come across the surgeon's worst enemy which is what? Speak up man! Blood you numbskull, you cut a patient he bleeds until the processes of nature form a clot and stop it. This interval is known scientifically as the bleeding time. You - what's the bleeding time?

Ten past ten sir.

MACNAIR

Fortunately attitudes and approaches to health care have been changing and by 1999 the pearl of wisdom that Liam Donaldson had heard from his teacher years before was helping to shape a new initiative.

DONALDSON

And that really had stuck in my mind all those years and when I saw Kate Lorig's work in California I felt this idea of a programme which empowered patients with chronic diseases helped to manage their own condition was a very powerful one and really a win/win - a win for the health service because it reduces people's visits to hospital but more than that a win for the patients because it puts them in absolute charge of their care.

MACNAIR

So at last we are recognising just how much patients can contribute to the management of their own condition, and actively encouraging them to get involved. This is a fundamental change in thinking from when I and many other doctors today first trained.

DONALDSON

In those days the idea of a patient playing an equal part in the decisions about their care would have been regarded as very strange and indeed I can remember in my clinical days

when I was a junior doctor patients who asked too many questions often had written in their notes - difficult patient. And these days that seems horrifying and laughable but that's what used to happen. And I think what this programme does is it just reverses that situation entirely and it says well really the patient - particularly the patient with chronic disease who's lived with the ups and downs of it over the years is the expert and the doctor and the nurses and the team are there to support the patient, rather than the other way round.

MACNAIR

David Jewell a Bristol GP and editor of the Journal of General Practice believes that change has been driven by patients themselves.

JEWELL

General practice has changed an enormous amount and I'll come back to that in a moment. I don't think it's the way the general practice has changed that has set the agenda for the Expert Patient Programme, what's changed here is the advent of self-help groups and their growing understanding that we're not fantastic at always understanding their needs or providing what they want or anything else. And that actually it is part of their responsibility to try and get the best out of the system for themselves, so it's not - as I said - it's not change in general practice it's the change in what we have to offer, which is vast and too big for most of us to understand or to hold in our heads all the time, on the one hand and I think it's the change in the nature of patients who've become more assertive, patients understand that they have to live with their conditions for longer than they a lot used to, it's those sort of changes I think which really set the scene for it.

ACTUALITY - EPP COURSE

LOCKE

I hope you've had a good week. It's been a beautiful week. But our agenda today we're going to start off looking ...

MACNAIR

It's week two of the EPP in Hammersmith and Fulham. The programme starts off with everyone reporting back on how they've got on with the action plans they prepared last week.

ACTUALITY

PITCHER

My action plan included pursuing the exercises that I've been doing for the calf muscles and I conscientiously pursued those. And then I did walk in the park, I've got these new raised shoes, as you know, and this is a question of getting used to the gait of that, which is quite difficult. And then ...

PAPA

My plan was to walk for three days - 20 minutes a day - but I manage and I walk five days ...

COURSE MEMBER

My long term goal when I set was to actually ride from here to Oxford along the canal. And I hoped I would be able to do that in a couple of months and now that's not going to happen ...

MACNAIR

I asked James why this is such an integral part of the course?

LOCKE

Goal setting is really the process of bringing people the dreams back into their lives and the structure for their dreams and a little bit of control. And you can reach your dreams through a process of action planning, small steps for example, and that's why action planning is so important. We try and get people to think about a goal that they'd like to achieve in their life, whatever that goal may be, however small it may be, it might just be walking down to the local post office to collect your pension for example or meeting your grandson that you may not have seen that's living overseas but setting a goal, looking at a goal, something that you really want to do and through the simple steps and the process of action planning will enable you to reach that goal.

ACTUALITY - EPP COURSE

MCCAULEY

... something you want to do, it's reasonable ...

MACNAIR

At the end of the session tutor Liz McCauley is handing out the next batch of action planning sheets.

ACTUALITY - EPP COURSE

MCCAULEY

... I'm going to walk a mile but you feel you can just walk just round the block that's fine. It's what's reasonable for you now.

PAPA

Yes this week I try to ...

MCCAULEY

Try - what am I hearing?

PAPA
Extend exercise as cycling.

LOCKE
Yeah but try, did you really want to use the word try.

PAPA
Okay yes.

MACNAIR
Any negative signs - do people sort of complain of anything, do some people find it's just not for them?

MCCAULEY
Oh I think you'll find that because a lot of people come on to the course and really have no idea what it's all about and it's not for them, they don't want to talk about their problems and it's fair choice, it's entirely voluntary and we just want to spread the word but we're not going to grab people off the streets or the doctor's surgery, we just want to let as many people know as possible that it's there and it's free and that you will gain something from it but you can't predict what it will be.

ACTUALITY - MILFORD ASSESSMENT AND REHAB CENTRE
Right everybody, the aim of this is to try and keep the ball on the parachute, so what you're trying to do is keep your arm as nice and straight and lift them as high as you can and obviously as you lift them so will the parachute come up...

MACNAIR
One reason why the NHS Expert Patient Programme might not suit someone is the generic nature of the course, where groups are put together irrespective of the conditions the patients live with.

At Milford Assessment and Rehabilitation Centre at Milford Hospital in Surrey, they run their own series of disease specific courses. One part of the programme here for people with Parkinson's disease focuses on exercises which have been carefully chosen to address the particular problems that arise in this condition. As I watched, the group struggled to control a huge parachute, as an exercise in controlling their arm movement.

ACTUALITY - MILFORD ASSESSMENT AND REHAB CENTRE
Really lift them, lovely, well done. Can we get to the ceiling?

POLLY

My name is Polly. It was a six week course for people with Parkinson's and I think most of us felt the - would find it very difficult to join in with other people but it was very well run, very happy, thoroughly enjoyed it, would like it to continue for much longer or at least more frequently. And I think it was the atmosphere in this particular hospital which has been so splendid. And it's been fun, I think that was very unexpected was the fact that it was so amusing as we all endeavoured to do all these extraordinary exercises which I've never done in a group before and it was - it really was very enjoyable.

MACNAIR

But would you want a course that wasn't specific to your condition?

POLLY

I'm not so sure about that. I think the thing that it was specific to Parkinson's was what made it viable because its disability is so different from the physical - just a physical disability. And one has a - starts off with an understanding of the other person's problems, which I think was helpful whereas a mixed course I think would be much more difficult to enjoy.

ACTUALITY - MILFORD ASSESSMENT AND REHAB CENTRE
MUSIC

MACNAIR

The members of this group are all in their 80s and they too have a course that is tailor-made to their condition. They're at risk of falls. The aim of the line dancing is to help their balance.

PUTTUCK

My name is Mary Puttuck.

TSINGKA

My name is Charlotte Tsingka.

PUTTUCK

Honestly since I've been here it's done so well for me, if I hadn't come here I don't think I'd even be walking about. I rely on this, yes I do, to keep me going.

TSINGKA

Well I came here because I lost my balance and when I came here first and the doctor asked me to shut my eyes I fell on top of him. He was very young and handsome so it didn't

matter. Anyhow I get all exercises here and since I feel much better. They introduced me to line dancing, which I didn't know what that was and I go line dancing twice a week and I feel very healthy since then and I am a very happy person.

WHITING

My name's Ruth Whiting and I'm a sister here. In one session we do half an hour of education, this can be nutrition, it can be about pacing, it can be about lifestyle changes and then we have another half hour of exercise, then we do the line dancing for half an hour, which is obviously for strength and balance and then we finish off with half an hour of relaxation.

MACNAIR

So these courses use some of the same types of strategies found in the NHS Expert Patient Programme but tailored specifically to the problems seen with the condition the group share. Another major difference is that this programme at Milford is delivered by health professionals not lay tutors.

Dr Charlotte Johnson, medicine for the elderly specialist at Milford, says that elderly people who grew up with a paternalistic health service may find the idea of patient centred medicine unsettling.

JOHNSON

The difficulty of that for us with this age group is that traditionally there's a paternalistic medical approach - the doctor always made the decisions - I don't know doctor, whatever you think. And modern medicine dictates that we're not supposed to practice like that anymore but in this age group a lot of them don't like that, so it's very difficult and you have to be able to pick out who wants you to take control, who wants to be given some control and try to strike a happy medium. Some people wouldn't be interested in coming to the group because they don't want to know, they don't want to know what bad things could happen, they don't want to think about it. Some patients will want any information you can give them, any support.

MACNAIR

As part of their course the Milford team are able to give out information which is carefully targeted to the condition. Is this a problem for the Expert Patient Programme?

LOCKE

I don't know anyone, to be honest, that's actually had real problems getting information. I think the important thing about this course is really - it's the process, it's teaching the people the skills of knowing where to go as opposed to the content. And that is the real difference I suppose between the chronic and the disease specific - how to get information and where to get that information from. And it's their responsibility to really be informed about their own particular

condition.

MACNAIR

So really the people need to take the tools that you give them, you're giving them tools to then work on their own specific conditions?

LOCKE

Ye ah we're giving them tools that people can use for any chronic condition they're living with. But it's the process as opposed to the content. In the hope that they're empowered to go to their resources, find out more about their condition.

MACNAIR

You teach them how to do something rather than what to do.

LOCKE

Exactly.

MUSIC

MACNAIR

Next week we'll take an analytical look at the evidence for this approach, and what the health professionals think. Does it live up to the hype?

MUSIC

ENDS

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