

# Living Better E-Bulletin

Living Better: Improving mental health and wellbeing of people with long term conditions

## Introduction:

Living Better aims to improve the mental health and wellbeing of people with diabetes, coronary heart disease (CHD) and Chronic obstructive pulmonary disease (COPD). The project is funded by the Scottish Government and will be running until March 2011.

The Living Better project is a three year, Scottish Government funded initiative, involving the Royal College of General Practitioners (Scotland), the University of Stirling, the Scottish Development Centre for Mental Health, Chest Heart and Stroke (Scotland), Depression Alliance Scotland, the British Heart Foundation (Scotland), and Diabetes UK (Scotland).

The project is working with 5 Community Health Partnerships (CHPs) and 10 GP practices across Scotland to address mental health and wellbeing in people with long term conditions. In 4 CHP sites the project is focusing on diabetes and/or CHD and in 1 CHP site Chronic Obstructive Pulmonary Disease (COPD). The pilot site CHPs involved in the project are: **Angus, South East Glasgow, East Dunbartonshire, North Lanarkshire** and **The Western Isles**.

## Living Better Research:

### How was the research done?:

To discuss how living with long term conditions affects peoples' mental health and wellbeing, patients with CHD and/or diabetes and COPD were selected from practice registers and invited to attend focus groups in their areas. Focus groups involving health, social care and voluntary sector staff working with these patients were also organised.

### Research Questions:

- How does Living with COPD, Diabetes and/or CHD affect People's Mental Health and Wellbeing?
- What Type of Support do these people Want and Need to Address their mental health and wellbeing needs?
- Do Health Professionals Working with these Patients feel Suitably confident/trained to Address Mental Health and Wellbeing Issues in these Patients?
- What has to be done at CHP and GP Practice Level to Develop Appropriate Support/s to Address These Patient's Mental health & Wellbeing?

### Methods:

- Working with 5 CHPs and 10 GP practices across Scotland Living Better reference groups consisting of appropriate health and social care staff set up in each site.
- Patients with diabetes and/or CHD & COPD selected from Diabetes, CHD and COPD registers.
- Twenty patient focus groups (involving over 200 people) were organised.
- Ten health professional focus groups (involving over 75 health care staff).
- The research findings are reported back to the CHP Living Better reference groups to help them develop appropriate plans to address the mental health and wellbeing needs of these patients.

The same questions and methods were used across all 5 participating CHP sites.

## Summary of Findings: Patients

### Living with COPD or Diabetes and/or CHD is both an Acute & Chronic Stress and Impacts on Patients in the Following Ways:

- Shock of being diagnosed with diabetes/ COPD and/or acute event around CHD.
- Feeling that family and friends do not understand the strains of living with LTC.
- Frustration over lifestyle change.
- Loss of confidence.
- Strains on family and wider personal relationships.
- Frustration.
- Anger.
- Guilt.
- Fear – especially among CHD and COPD patients.
- Financial worries.
- Social isolation.
- Loss of purpose in life.
- Restrictions to lifestyle and employment opportunities.
- Embarrassment.
- Accessibility/Transport problems.
- Stress in lead up to and after the annual or 6 monthly review.

### Quotes from Patients:

#### The Shock of Diagnosis

I thought I'm getting home because I feel better, I'm brand new after the night in the ERU and the guy came out and says 'no, you've had a heart attack'..... my brain wasn't taking it in. I says 'not me, how have I had a heart attack?' I says 'I'm only 35, how can this be...?' He says 'Believe me wee man, you've had a heart attack'..... it was if somebody just pressed a big pause button on your life'.

*North Lanarkshire Male with CHD*

#### Living with a Long Term Condition Can be Frightening

'I would say (the feeling) is fright. When you really can't get your breath in the middle of the night and you wonder... your heart's racing... and you wonder if it's the last breath you'll ever take'.

*East Dunbartonshire Female with COPD*

The only thing that does concern me is the fear that I might lose a leg or something like that or go blind, I wouldn't want that. My mother cared for my father for many years and I wouldn't like to subject my wife to that.

*Western Isles Male with Diabetes*

#### Financial Concerns

'Well I'm having terrible problems with that (disability allowance) right now. You know the way you've got to renew it every so many years, mine's is up for renew and I got a letter back, they took everything off me. And you get all upset if you've got to face all these people it's like being in a court. I'm waiting every day for a letter. I'm fighting with them just now, so that's quite stressful'.

*South East Glasgow Female with CHD*

#### Disruption to Lifestyle/Strain on Relationships

It was very difficult; in fact I still find it difficult now. I've been out of art teaching for five years... and I'd been teaching for 30 years and it was something I loved doing. Obviously it's a matter of coming to terms with things all the time, finding alternatives and luckily I've got interests and hobbies which I've managed to divert my creative instincts into. But it's something that I've had to work out myself, and I don't think it's been easy for me .. or my partner for that matter'.

*Western Isles Male with CHD*

'I have chest infection after chest infection. I used to go out with friends, now you think 'I won't bother' because I'm too slow, not that they say that, but you feel it within yourself, so you're inclined to retreat into yourself. So it has a dreadful impact when you've had it for a long time. In every respect it completely and utterly destroys your life'.

*Female COPD Patient*

#### Transport Problems/Social Isolation

Well if you could walk properly with good breathing it's no problem. I'd go for a walk or something else, but when you do have a bit of a problem going up hills it's necessary that you can get a bus. But you don't always get a bus to the exact place, and if you don't have a car you're a bit scuppered unless you've got someone there that will give you a lift. So it's not always possible to use some of the facilities they've got unless you're paying for taxis all the time which is out of the question... So you're stuck in the house which is no good really.

*East Dunbartonshire Female with COPD*

## Summary of Findings: Health Professionals

- The Quality Outcomes Framework (QOF) mental health questions feel like a 'tick box', a 'numbers' or a 'paper exercise'.
- A feeling of 'what do we do next?' after QOF questions or using HADS/PHQ9.
- Practice and Specialist Nurses would like more time with patients to tease out mental health issues.
- The stigma of mental illness remains a problem in addressing mental health and wellbeing in people with these conditions.
- Need for greater knowledge of, and how to access, existing social support services.
- Greater integration of appropriate community health, voluntary and social care services, especially between CHPs, GP practices and social services.
- Practice and CHD/Diabetes/COPD specialist nurses expressed a desire for more mental health and mental well-being awareness training.
- Greater need to raise awareness in primary care staff of the importance of mental health and wellbeing in CHD, diabetes and COPD care.
- More information about LTC relevant NHS and non-NHS services at CHP level.
- Stronger partnership working with local authorities to utilise and also develop social support services for patients with LTCs.

### Quotes from Health Professionals:

I think the screening questions are seen as a sort of tick box exercise.. I think the questions are 'do you have low mood?' maybe the wording of it, it's not about mental health it's about illness, and people maybe don't see that 'oh well no, I'm not depressed' that's not a word that they associate with their illness. Also there's not time, you know, the nurse has got twenty minutes/half an hour, she's got to do their feet, pulses, everything else [laugh] and it's 'are you depressed?' 'no', that's fine, move on!

*CHD Nurse Specialist*

Its ok saying practice that day than if it had been a quiet day...holistic care....I think it depends on how much time you have with the patient but if you've got 20 patients in a morning people might find there'd be less holistic care...we're all in the same boat if you are constrained by time we're less likely to pick up something in the first place.

*Health Professional*

'The depression screening came in without the training. We've been floundering for a couple of years....the depression questions just came in handed down really, that's quite typical of the way things happen, its too top down'.

*Diabetes Nurse Specialist*

I think the annual review probably does give the chance to identify it (depression), but as we are saying, that's where maybe there's the gap. It's like 'okay, what do we do with this patient?' Because a lot of them, they don't want to go onto the anti-depressants as well, you know...they don't want to admit they're depressed'.

*Diabetes Nurse Specialist*

'When your talking about getting patients to use other services to help them, there are so many things that are out there but people are not aware of what's available and I include us and patients in that. I didn't know about that exercise class for example'.

*Practice Nurse*

'QOF questions are progress in tackling this issue but a lot of us don't like using PHQ9 because if we're sitting speaking to the patient, you print off this sheet, give it to them, it's really much less professional I think most of us feel, but we have to do it, so...'

*General Practitioner*

I think in terms of training, with practice nurses, it would be training in detection rather than assessing severity, that would be us as GPs

*General Practitioner*

# Moving Forward: Recommendations from the Focus / Reference Groups

## Types of Support Patients Wanted/ Needed to Help Ease the Stresses of Living with COPD, Diabetes and/ or CHD:

- Broad social support services – Levels 1 & 2, e.g., support classes (dietary, exercise, general talking) to share experiences and exchange information.
- Easier and more rapid access to health worker or fellow patient/s to confide in on a one to one or group basis.
- General talking support, either face to face or on the telephone.
- Access to condition specific exercise classes to help manage their physical condition so as not to feel awkward in the event of getting into physical difficulties e.g., coughing bouts in COPD patients.
- Financial/benefits advice to address financial consequences of living with these LTCs.
- Greater support with and access to public transport.
- More information about locally appropriate support services provided by health social care and voluntary sector services.
- More 'talking time' with nursing or other health/social care staff.
- Counselling.
- Greater advice & information about drugs they have to take for their condition.

## Some Recommendations from Focus Group Findings to CHP Reference Groups:

- Greater mental health and mental wellbeing awareness training should be provided to nurses, AHP and health support staff working with COPD, diabetes and/or CHD patients.
- Each CHP reference group should discuss how to develop Partnership working with relevant local authority and voluntary sector services to address access/transport issues, financial/benefits advice, exercise/leisure facility issues and other social support needs of people living with COPD, diabetes and/or CHD.
- Greater recognition of the benefits in developing appropriate social support services should be discussed by each Living Better CHP reference group.
- Identify the key players in each of the 5 Living Better CHPs who will facilitate the coming together of appropriate staff to develop the collaborative working required to meet the mental health and wellbeing needs of patients living with CHP, diabetes and/ or COPD.
- Social support services are non-complex and low cost interventions and have the potential to bring significant benefits to these patients.
- Nurses, AHP and health support workers, in collaboration with social and voluntary sector colleagues, have a vital role to play in addressing the mental health and wellbeing needs of patients living with COPD, diabetes and/or CHD.

## The Next Steps:

Five individual pilot site reports based on local focus group findings have been produced and will be available to download from the Living Better website shortly. These reports are being used to steer the work of the pilot sites, as well as contributing to national knowledge about the mental health needs of people with long term conditions. The pilots will be working to implement some of the recommendations from the focus groups over 2010. The next research stage for Living Better includes patient surveys and clinical audits in selected GP practices across the 5 sites.

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Further information and full research reports will soon be available on our website  
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