



Royal College of
General Practitioners



The Scottish
Government



scottishdevelopmentcentre
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The Living Better Project

Addressing Mental Health and Mental Well-being in People Living with Diabetes and/or CHD

Feedback from Angus Focus Groups (1)

May 2009

Summary

Scotland has high and growing rates of diabetes and Coronary Heart Disease (CHD). Depression and/or anxiety are increasingly common in these patients and can negatively affect the outcomes of diabetes/CHD. Given current methods, is primary care effectively equipped to screen, diagnose and treat depression and/or anxiety in these patients? Recent research involving diabetes and CHD patients and health professionals working with them suggests not, but the solutions are not necessarily complex or expensive.

Working with 6 Community Health Partnerships and 12 GP practices across Scotland, patients with diabetes and/or CHD were randomly selected from the computerised Quality & Outcomes Framework (QOF) management system registers. Focus groups involving these patients and practice staff were conducted to discuss mental health issues and how these could be addressed.

Data analysis from focus groups with people with diabetes and/or CHD and health professionals working with them in Angus CHP suggests the impact of illness differs across these two conditions. However, for both conditions, social support was an important buffer to the stresses of living with diabetes and/or CHD. In addition, a lack of or weak social support was identified by patients and professionals as increasing the risk of psychological distress, and negatively affecting mental health and well-being in general.

Recognition of psychological distress is an important function of General Practice, yet approximately 50% of patients experiencing mental health problems remain undiagnosed and untreated. Social support is a non-complex, low cost intervention. It has the potential to bring significant benefit to these patients. Greater consideration of this important aspect of mental health and well-being, during screening, assessment and treatment must be increasingly considered in patients with diabetes and/or CHD.

1.0 The Living Better Project: General Background

The Living Better project is a three year partnership initiative involving the Royal College of General Practitioners (Scotland), the University of Stirling, the Scottish Development Centre for Mental Health, Depression Alliance Scotland, the British Heart Foundation (Scotland), Chest Heart and Stroke (Scotland) and Diabetes UK (Scotland). The project aims to lead the development of improved care for people with diabetes and/or Coronary Heart Disease (CHD) who also have mental health needs which research has found can often go unmet. The project will work with 6 Community Health Partnerships (CHPs) across Scotland to identify current service provision and consider and attempt to deliver new ways to improve care. In each of the 6 participating CHPs a Living Better Reference Group will be established, consisting of service users, key health and social care professionals working in diabetes and/or CHD, and key strategic planners. This Reference Group will be a vehicle for assessing existing service provision for this population of patients, and developing and implementing new stepped care pathways to address mental health issues in people with diabetes and/or CHD. Two GP practices in each participating CHP will work closely with the Living Better project to identify appropriate patients who will be involved in the Living Better project itself and also in the evaluation of the Living Better project.

The principal goals of the Living Better project are;

1. To improve the detection and diagnosis of mental health problems and promote mental well-being among people with long term physical conditions, specifically Chronic Heart Disease and/or diabetes in primary care
2. To improve the provision of appropriate interventions and treatment including medical and non-medical options to improve mental well-being and general mental health in people with diabetes and/or CHD
3. To ensure that responses reflect patient choice
4. To improve the Community Health Partnership's responses towards addressing mental health and well-being and mental illness in people with long term conditions in terms of flexibility, communication, and shared learning
5. To strength partnership working within these CHPs
6. To share the learning across Scotland

Community Health Partnerships are key structures for developing greater joined up care in the community. Living Better aims to lead and develop an approach that CHPs could implement to meet the mental health needs of this population; identifying transferable learning as we identify what needs to be in place at a local level to deliver stepped care pathways (such as training and skills development, or service developments, or establishing partnerships with other sectors etc.). The project aims also to learn how well equipped CHPs are to support and develop this type of initiative in primary care.

2.0 Emotional Consequences of Living with Chronic Physical Illness

It is well established that depression is highly prevalent in people with chronic physical illness, and should be treated. Up to 33% of patients develop depression after a myocardial infarction [1] and meta-analysis has shown that depression is associated with a doubling of mortality in CHD [2]. It is estimated that one in three patients with heart failure and one in five patients with CHD experience depression [3] Depression is also found in 30% of cases of diabetes [4]. Such 'co-morbidity' of physical and mental health problems are exacerbated by socio-economic deprivation such as exists in certain areas of Scotland [5,6]. A result of this recognised

prevalence is that the revised Quality and Outcomes Framework (QOF) of the GMS contract incorporates case finding for these groups [7]. Screening for depression in patients with diabetes and Chronic Heart Disease was added to the QOF in 2006.

Recognition of significant psychological distress is an important function of general practice, and depression and anxiety together form the most common reason for patients consulting a GP in Scotland. Approximately 50% of patients with such mental health problems remain undiagnosed and un-treated [8-10]. In deprived areas, the prevalence of mental illness is higher, and the detection rate lower than in more affluent areas [11a]. A recent study on depression in Scotland found that around half of patients with significant symptoms were not identified by their GP as suffering from a depressive disorder (11b). Given the higher demands placed on GPs by patients with chronic physical illness together with the significant time constraints GPs face, it seems likely that depression in patients with chronic illness is massively under-diagnosed (hence the rationale for the QOF points), and this is likely to be exacerbated by deprivation.

There were 219,963 people with known diabetes in Scotland recorded on local diabetes registers at the end of 2008, which represents 4.3% of the population. In the 2007 diabetes survey, 209,706 people (4.1%) were reported. It is estimated that there may be as many as half a million people in Scotland with diabetes within the next ten years [12a]. The Diabetes Action Plan for the Scottish Diabetes Framework [12b] included aims to "improve access to psychological and emotional support for people with diabetes in all parts of Scotland" within its 9 key promises. This includes aims to improve the identification of depression and anxiety among those who care for people with diabetes. The inclusion of aims around psychological support has been welcomed by Diabetes UK as consultation with their members has highlighted psychological needs as is a key concern due to a perceived lack of input from health services in relation to psychological needs. One review indicated that treating depression can improve glycemic control [16]. Collaborative stepped care, including the use of enhanced education and support, antidepressants or problem solving delivered in primary care for patients with diabetes and depression was shown to reduce depression severity, increase patient rated improvement and increase patient satisfaction with care [17, 18].

Coronary Heart Disease (CHD), also known as Ischemic Heart Disease, is one of the leading causes of death in Scotland. Around one fifth (19%) of premature deaths in men and more than one fifth of premature deaths in women are caused by CHD. Approximately 140,000 people in Scotland have had a heart attack; 260,000 people are suffering or have suffered from Angina (the commonest form of CHD). Scotland has one of the highest death rates from CHD in the western world. This has been attributed to high rates of smoking, poor diet and deprivation. It is estimated that 14.9% of Scottish men and 14.5% of Scottish women are living with some kind of cardiovascular disorder. It is estimated that 82,000 patients with CHD and 24,700 patients with stroke or transient ischaemic attack visit their GP each year. The prevalence of all conditions increases markedly with age. [13a, 13b]. There is emerging evidence that treating depression improves morbidity and mortality in relation to CHD, which may be due to improved compliance for cardiac medication [14]. Pharmacological treatment for people with CHD and depression can be complicated as some antidepressants have cardiac side effects, and herbal supplements (such as St. John's Wort) can interact dangerously with cardiac drugs [15]. Hence it is recognised that management can be clinically complicated and that there is a gap in best practice for treating depression in CHD patients, and in general studies support the use of multidisciplinary approaches in providing care [14, 15].

Overall the evidence demonstrates the significant morbidity associated with having depression and CHD and/or diabetes and the increased likelihood of depression occurring within these populations. The evidence indicates there can be significant benefits obtained by improving best practice in relation to these patient groups and stepped/collaborative approaches offers the most promising mechanism for quality improvement for these patients. In this proposed project we aim to draw on best practice in depression management as outlined in recent NICE guideline, and on evidence-based guidelines currently being developed by the Scottish Executive Health Department as part of the national Mental Health Delivery Plan (2006).

3.0 Addressing the Challenge of Long Term Conditions: The Policy Context

The way health and social care is being planned and delivered in Scotland is changing. To address the challenge of growing numbers of people with chronic illnesses, health and social care organisations have been directed by the Scottish Government to work together in partnership with each other, with the voluntary sector and with patients and carers (19b). On a wider level, under current Scottish Government health policy, Health Boards and Local Authorities are assessed on their levels of partnership working and are seen to be progressive if they deliver community partnership working; fair, equitable and accessible services for service users; put patients and carers at the centre; provide services that are as local as possible; and test out new ways of delivering integrated services in the community (19b).

Alongside the recent progress and improvements made with managing long term conditions, greater responsibility for self-care and supportive care is now on people living with diabetes and/or CHD and their families and carers. Increasing responsibility is also being placed on community based health and social care organisations and the voluntary sector to provide and facilitate community based treatments and support for people with diabetes and/or CHD.

In light of this, meeting the challenges of living with long term conditions has become a major policy priority for NHS Scotland and its partnership agencies. Following the publication of the Kerr Report in 2005, *'Building a Health Service Fit for the Future'*, the Scottish Executive responded by producing *'Delivering for Health'*, a statement on the future plans for healthcare in Scotland. The model of care proposed within *'Delivering for Health'* (21) was based on the principle of integration, with patients and carers playing a central role in decisions about their care. Both policy documents underlined the need, if services are to be improved, of developing partnership working between the NHS, other public sector and voluntary organisations. This requires; (i) developing efficient partnership working between health, social care and voluntary sector organisations, with patients and carers at the centre of such partnerships and (ii) the need for a 'whole systems' approach to providing services, with each partner linking together to form one 'whole system' of care, again with patients and carers at the centre.

In October 2007, the new Scottish government launched their health policy action plan *'Better Health, Better Care'*. The proposals focused on the evolution of existing health policy as opposed to any radical departure from fundamentals contained in the Kerr report and *'Delivering for Health'*. The new and developing model of healthcare delivery in the NHS is through multi-professional teams crossing traditional professional, geographical and organisational boundaries. One example of this is the development of Managed Clinical Networks (MCNs) where the emphasis is on cross-boundary working to ensure equality of care and outcomes. Managed Clinical Networks deliver diabetes and CHD services across different sections of Scotland.

They are important in the context of delivering information to people affected by diabetes and/or CHD as *'they lead to clearer information for patients and carers'* (19b). Strongly linked with the Managed Clinical Networks of care is the centrality of the patient journey. This concept sees patient care as a combination of services involving health promotion, preventative care and follow-up care and support in the community from a range of health, social care and voluntary sector organisations working together.

To address the challenge of managing long term conditions in Scotland requires a culture of trust and co-operation between different organisations. An important driver for achieving greater partnership working, greater patient and carer involvement, and ensuring effective delivery of quality healthcare are the Community Health Partnerships that operate in every Health Board area of Scotland. A key role of CHP's is in developing systems of care for the management of chronic illnesses in the community, and supporting the increasing number of patients with more than one long term condition at home and in community settings (19b).

It is becoming increasingly recognised therefore that peoples' physical and mental health and well being are not separate entities and must be intrinsically linked. Living with a long term condition and experiencing mental ill-health can be costly to the individual, their family and community and can result in a considerable loss of human potential and resources. It doesn't have to continue like this. Research on diabetes and depression, for example, has shown that social support (an important aspect of positive mental well being) can have a helpful affect on patient self-care and diabetes outcomes (39); and in people with coronary heart disease, effective treatment for depression has been shown to enhance quality of life and to improve physical, social and emotional functioning (43).

Yet, in autumn 2007, after reviewing the management of long term conditions across Scotland, Audit Scotland published a report in which they stated *'people with more than one long-term condition are less likely to be receiving joined-up care across all the services they receive'* (p.40). Their report recommended improved partnership working at primary care level between health, social and voluntary care providers in order to integrate services for people with LTCs. The report also recommended that Community Health Partnerships (CHPs) should have a key role in co-ordinating this

4.0 The Living Better Project: Research Component: Findings from the Focus Group Meetings

For the initial research phase of the Living Better project a series of focus group discussions with people in Angus who have diabetes and/or CHD and health professionals who work with these patients was organised. A total of 5 focus groups took place, three involving patients (attended by over 50 people) and two with health professionals (attended by 14 people).

The findings from the focus group data will be used to inform the Living Better reference group meetings in the participating CHPs. Section 5 of this report contains the main findings from both the patient and professional focus groups.

4.1 The Patient and Health Professional Sample

The patient sample was a random selection of patients on the diabetes and CHD registrars of the two participating GP practices in Angus CHP. Health, social care and voluntary sector professionals were identified through discussions with Angus CHP staff working in long term conditions, diabetes and/or CHD.

4.2 Analysis of Focus Group Data

Analysis of the data was thematic. Thematic content analysis is a validated and effective approach for answering questions about the most significant issues raised by a particular group of respondents and/or for identifying typical responses from interviews and focus groups (20).

5.0 Summary of Key Findings from Patient and Professional Focus Groups

The following tables 1-4 summarise the key findings from the focus groups whilst table 5 summarises the key themes and sub-themes from both the patient and health professional focus groups.

Table 1: Summary of what Patients said about the Emotional Consequences of Living with Diabetes and/or CHD

- Shock of experiencing cardiac event and/or having to undergo surgery
- Shock of being diagnosed with diabetes and/or CHD
- Stressful build up to annual review and stresses after annual review if 'bad news' about condition
- Strain on personal and family relationships
- Anger
- Feeling Isolated
- A feeling that other people think you are exaggerating the effects of the condition/s
- Frustration at people who don't have the condition/s and not understanding the consequences of its effects and having to live the condition/s
- Getting into a 'rut'
- Lack of support if single
- Negative financial consequences
- Strain of having to re-adjust lifestyle
- Worrying about effects on immediate family

Table 2: Summary of what Patients said about what happens to them and the type of support they would like in place to address the emotional consequences of living with Diabetes and/or CHD (see section 6.0 for patient quotations)

- Due to time pressures, GPs can't spend the time to address and tease out some of the mental health and well-being issues that living with diabetes and/or CHD produce.
- Few patients would openly discuss their mental health or even refer to living with diabetes and or CHD as stressful. Most stated that they *'just got on with life'*.
- Consequently the following professionals should be available either for a 30 – 40 minute confidential face to face or telephone discussion: diabetic counsellor specialist diabetic nurse; practice nurse, nursing assistant.
- Support classes such as exercise, cooking classes are good for mental well-being and mental health. They *'occupy the mind'*, *'get us out the house'*, *'help forget about the condition'*, *'provide opportunity to share experiences'*.
- Support groups have a beneficial social side.
- Greater support after diagnosis/episode and before and after the annual review which can be stressful.
- Having someone with the same condition one can share experiences with
- Having the opportunity to pick up the telephone or go on-line and discuss particular problems, especially for people who live alone.

6.0 What Patients said in the focus groups about living with the Condition and the impact on their mental health and well-being

6.1 CHD Patients: Initial shock of experiencing cardiac event and/or having to undergo surgery

CHD Patient 1: *I think the first probably week/week and a half, quite an emotional time. And I was only home about three days and something silly happened and I just burst out crying. And it wasn't until I went back and saw the consultant he said to me while we were talking, he said 'by the way, how did you find it when you got home, were you emotional at all?' And I told him, and he said 'oh yeah, we find that'.*

CHD Patient 2: *I think one of the problems is confidence. When you first have a problem with your heart, it does affect your confidence as to what you're going to be able to do in the future. And it's only by starting to do it that you really find out just how far you can go or what the restrictions are, like going up hills or upstairs or whatever. But certainly it does affect you quite badly to start with. It certainly did with me anyway.*

6.2 Diabetes Patients: Shock of Diagnosis and the importance to them of key others understanding what it's like to live with the side effects

Diabetes Patient 3: *I'm from here but lived in England for a good few years but when I retired I moved back here as I'm a keen painter and the landscapes here are fabulous. My site started to go. I've had four operations on my eyes, none worked. I eventually lost my sight.....I didn't get depressed. I knocked a couple of walls down myself! I got it out my system you see. I knocked the walls down, that's it. I'm okay now.*

Diabetes Patient 10: *It's fundamental that you have a partner or somebody else that is aware of the condition and is accessible all the time. I find that quite often my family do not understand my tempers at times. I do get bad tempered I admit it, and my family can't understand why I'm like this. People think you exaggerate I expect there's a desire not to believe. It makes you feel as if you're telling lies.*

Diabetes Patient 18: *I find that I get angry with my daughter-in-law who refers to my son, who also has diabetes as grumpy granddad, which I think is not fair. I know he probably does get grumpy but he works hard and I think possibly they don't really understand that being a diabetic can affect you emotionally.*

Diabetes Patient 12: *You gets frustrated..... I have one friend and she just seems to totally ignore the fact that I've got it! Well, you know, she'll visit and bring me boxes of chocolates, you know, all fancy biscuits and things and totally inappropriate if you know what I mean? I think the first one is disappointment, and then a little bit of anger and then 'well why?'*

Carer of Diabetic 1: *They're very, very good and supportive on the diabetic issues, you know, any problem with a Diabetes related question is fine, but not on the emotional side.*

6.4 Economic Stresses of Living with CHD & Diabetes

CHD Patient 3: *If you go and try and get a job, as soon as you mention anything about your health they don't want to know you. Then there's the hassle you get off the social who think that you should be working, well it's not as easy as that, I found the (disability allowance) assessments there very stressful.*

CHD Patient 4: *The time when you tick at issues like insurance or there are times when society comes in on you and gives you a reminder, a wake up call, that you've got a problem. If you want to go abroad or something, that is when suddenly you've got an issue and a stress. And I'm insured with The Royal Bank, and up until now they insured me for Egypt, they insured me for Rome, Paris, whatever. And they said no, I felt dreadful. I couldn't understand it, but they gave me a broker and it's cost me almost £400. Getting help and advice with some of the economic problems would be helpful but I think I'm like most people I'd want to do that privately.*

6.5 Benefits to Mental Health and Mental Well-being of Getting out and Going to A CHD Support Group

CHD Patient 6: *I still find that going to the rehab which you were booked in from the hospital and you got ten weeks, ten weeks to Stracathro I went, and you get to know how much exercise you can do and how much you can't, and the Borg system so that you know that you're not doing too much. You also have a monitor on for the first couple of weeks so that you can see what your heart's doing.*

CHD Patient 7: *Yes, I've been and it's well supervised. There are physiotherapists there and it lasts for ten weeks, you can pass onto the second stage if you wish. There's one in Forfar and there's one in Montrose. I think there's one just starting in Lawrence Kirk.*

CHD Patient 9: *The Angus Cardiac Group is fantastic. I go to the physical training twice a week, it's really phase four, but I've done phase three I'm now on phase four. I go twice a week, it's wonderful. You feel good, you know, checks on your weight and that's why I get weighed once a month there's a very social side too. There's a cup of tea and a crack after your circuit training. It's at the Seminary, there's one in Kirrie and one in Forfar actually.*

CHD Patient 10: *It's social thing, it's not just fitness and medical. You don't really discuss your problems in the group. A fairly social get together, you know, that's all it is really. A cup of tea and a biscuit and blether, you know, it's good.*

CHD Patient 11: *I would say the only thing that I think might help the people that are not fit to go to the health place, it would be quite a good thing to have somewhere, a meeting maybe once... it doesn't need to... once every two or three months even, just to have a meeting and people discuss what's bothering them.*

CHD Patient 12: *There is a group in Kirriemuir it's called Primetime. They have a monthly meeting and they have a speaker that comes and gives a talk. Some are very interesting and some are very boring, but at least you're meeting up with a lot of other people. Here's a theatre group and a gardening group Those groups usually meet once a week, you know, the groups within the main group, and it's quite good. They do a Christmas lunch and all this sort of thing, it's quite interesting. It gets you out.*

7.0 Health Professional Focus Groups

Table 3: Summary of what Health Professionals said about challenges of addressing mental health and well-being in people with Diabetes and/or CHD

- A lot of people with diabetes and/or CHD in Angus, especially older people are unwilling to speak about their mental health and well-being even with a health professional
- The stigma of mental ill-health remains a problem. Patients still see mental well-being equated with mental illness but we know that's at the other end of the spectrum.
- Patients often don't tell health practitioners how they are really feeling when they are asked 'how are you emotionally'?
- Whilst improvements in physical management of diabetes and/or CHD have significantly improved in last 10-15 years similar progress has not occurred in addressing psychological consequences of these conditions.
- Communication with diabetic and/or CHD patients remains challenging for health professionals unless they know the patient well.
- The actual QOF questions and pre-questions are rather basic/crude.
- We use HADS or PHQ-9 but there isn't much done beyond the recording. We write down the number but what do we do next?
- We get taught that health is social, psychological, biological, physical and environmental but the reality is its still split into physical and mental in most parts of primary care. Health practitioners are aware of it but it's difficult to get the time or the inclination to do something about it we are so busy with our own tasks.
- Part of the problem is that the community mental health teams are essentially dealing with the more moderate to severe patients with depression and anxiety disorders and neither have the time nor see it as their remit to address health promotion or the milder forms of anxiety/depression in this group of patients.
- There is a long waiting list for Psychological therapies.

Table 4: Summary of what Health Professionals said about what should be done to address the mental health and well-being of people with Diabetes and/or CHD

- We need to start addressing depression and/or anxiety in these patients at Level 1 which means that people won't have to go anywhere near the mental health services.
- Greater integration of appropriate community services, especially at CHP and GP practice level
- Identifying those organisations who are providing level 1 support and ensuring health and social care organisations know (a) what they are doing and (b) how to refer/inform patients to/about them
- The focus needs to be more on how these patients live the most fulfilling lifestyles possible with their particular LTC meaning greater attention to their mental well-being and mental health and not just how to address mental illness.
- We need to involve the voluntary sector more both in terms of the support they offer but equally importantly the information they provide especially around financial matters which can ease the stress of living with the conditions
- Psychological services don't see long term conditions as a priority; something should be done to get them more on board.
- Greater focus on mental health promotion in long term conditions staff at CHP and GP practice level.
- Training of diabetes, CHD and practice nurses in mental health awareness raising and how to address these patients' mental well-being and mental health needs
- We should start to look at 'brief intervention workers' who might not necessarily be university trained with a degree qualification, but received appropriate training to support these patients.
- More trained counsellors who could attend phase 3 and phase 4 CHD classes.
- Training up our expert patients to share experiences and provide advice, guidance and appropriate support

6.0 Summary of what Health Professionals said in the focus groups about what is, and should be, happening in the community.

Health Professional 1: *People from my understanding often when we get a diagnosis and before we know where we are, we're into talking about how it can be medically fixed, you know, how it can be sorted medically. But I think there's a huge miss in how it's affecting people psychologically, because this is a huge milestone in your life that probably tells people that, you know, 'I'm not going to be here forever', and I don't think we're particularly good at dealing with that side of things. People are just expected, I think, just to get on with it and be content with very good medical treatment, but there's a huge miss on the psychological side.*

Health Professional 2: *They'll talk, I mean, in a group situation in particular, they'll talk about the pains in their legs or their head, or their blood pressure or whatever, but they won't talk about their mental attitude towards their illness. And I think there are an awful lot of undiagnosed mental problems for that very reason, and particularly amongst older people where there's still stigma attached to having any*

sort of mental issue, you just don't talk about it, you don't admit it. And maybe it's with younger people as well, I don't know, but it's certainly with older people.

Health Professional 3: *I mean, I put my hands up and say that I don't think health's currently designed in such a way to do that, and we do put some practitioners out their comfort zone by addressing 'how are you?', never mind 'how's your blood pressure?', but 'how are you?'*

Health Professional 4: *I think it's really interesting that things like the HAD score, you know, the scoring that's done around your anxiety and depression and things, the HAD scoring and things like that is done, it's done and it's recorded for cardiac patients in particular – I can only speak for that group fortunately at the moment – but it's done but there isn't much done beyond that recording of it bit. We write the number down, but what do we do next?*

Health Professional 5: *The current contract as it's defined with both cardiac disease and diabetes, which are the only two which ask the question, currently in other chronic diseases they don't do it yet, or not as a standard – is there isn't anything there, the activity is ask the question and go on and do the full screening, but it doesn't define what practitioners do with the problem thereafter.*

Health Professional 6: *How would you get people to (a) they know they're not feeling 100%, they know that they're worried about things, how do they get people to express how they're feeling in terms of their emotionality and how do we, as practitioners, make it easy for them to do that? What is it we need to do to say 'listen, it's alright to feel like that'.*

Health Professional 7: *You don't need a prescription to talk to somebody, you know, it's like talking treatment, it's kind of free. But everything's on the time line and I know that, for example, the pressures that some of our general practitioners feel on a seven minute or a ten minute consultation. I have to be honest, by the time they've done that whole thing of 'let's check your blood pressure, check your pulse, check your weight, check your wounds...', by the time all of that is done and the question of, you know, 'in general is everything alright?' That's the ten minutes is up.*

Health Professional 8: *Because everybody knows the minute you open that can of worms around 'right, we've done the numbers...' which is how it's been tackled with me and the practitioners who have looked after me is 'right, we've done all your numbers, let's have a wee chat Mary about how you're feeling so, you know, this isn't about your blood pressure and things, are you sleeping alright, how is your appetite, I've noticed you're losing weight and I'm wondering about this...?' That's a whole different ballgame when the door is opened, and that's what needs to happen. The door needs to be opened and people need to be guided through that journey, rather than the door is never opened for you and what you're asked to do is tick boxes that remain effectively behind shut doors.*

Health Professional 8: *I was a nurse previously, and at one time was a general nurse who worked in the medical side of things and we used to see lots of cardiac people coming in the door, and I was also a mental health nurse. I was always quite struck at the difference between – and I think to some extent we still see this – that when I worked as a general nurse I was almost expected to forget all the mental health training that I'd had, and as soon as somebody started to step over into the emotional side of things, it was like 'oh we don't do that here', you know, 'that's the*

mental health crowd that deal with that'. And equally, when I worked in mental health, I wasn't almost expected or allowed to exercise all the skills I'd learned as a general nurse. So when somebody became physically unwell, people in the psychiatric hospitals didn't want anything to do with them, you know, and that's a big sweeping statement, but they would get sent over to Ninewells and then we would have to send people over to sit with them because it was expected that general nurses didn't know how to look after people who were in emotional distress. And I just found that was a real dichotomy for me because when we learn as nurses, we learn about the whole person.

Table 5: Similar Themes and Sub-Themes that emerged from Patient and Professional Focus Groups

Key Themes	Sub-Theme/s
Importance of Speedy Access to Support	Importance of rapid access to support, decision-making and accessing services; Access to experienced and knowledgeable professionals; Access to people with the same condition to share experiences Reassurance of knowing support and information is available.
Importance of Support being Person-specific	People with diabetes and/or CHD have a variety of support needs; It is important to be aware that each individual's situation is unique and therefore so are their requirements. Information & support needs are dependent on person's individual circumstances.
Benefits of Sharing Experiences with Fellow Patients	For many people, shared experience is important in living with diabetes and/or CHD and opportunities to discuss with fellow patients is important
Benefits of Informal non-medical, non-psychological support e.g. exercise, cooking classes etc.	Both patients and health professionals underlined the importance of informal non-medical, non-psychological support such as groups linked to addressing exercise, diet and cooking where patients could chat informally, not necessarily about their physical health or mental well-being.
Importance of Confidential One-to-One Support	Importance of one-to-one confiding one's personal problems with a diabetes/CHD professional, or a Practice Nurse or a person with diabetes and/or CHD
The Importance of Social Support to both Mental Well-being and Mental Health	Data analysis suggests the impact of illness differs across these two conditions. However, for both conditions, social support was an important buffer to the stresses of living with diabetes and/or CHD. In addition, a lack of or weak social support was identified by patients and professionals as increasing the risk of negatively affecting mental well-being and mental health.
Users Want an Accessible, Informal and Neutral Venue	Importance of accessibility; Importance of friendly, open environment; opportunity to discuss non-diabetes/CHD related issues, having a 'neutral' venue.
The Value of Effective Partnership Working	Effective partnership working improves communication between health, social care and voluntary sector agencies working among people with diabetes and/or CHD in Angus; In the opinion of health professionals interviewed in the focus groups, users of services directly benefited from effective partnership working

7.0 Comment and Observation from Initial Analysis of Focus Group Data

From those people who attended the focus groups, over 90% were aged 65 years and over. As a number of health professionals stated in the focus groups, research has shown that for many people in this age group, talking about their mental health (indeed detecting it by using depression/anxiety scales such as HADS and PHQ-9) can be difficult. This was more the case with the diabetes patients than the CHD patients as one would expect. Patients in the focus groups, even though they did not talk about mental health (and some even refused to use the word stress) did explain and discuss that living with diabetes and/or CHD was demanding and posed significant problems.

As highlighted in section 2, research in the wider population has shown for some time that living with a long term condition such as diabetes or CHD can increase the risk of these patients developing depression/anxiety disorders. This is not surprising as a diagnosis of diabetes or the onset of CHD is a major life event and research has shown consistently (and not just in the case of long term conditions) that life events increase the risk of onset of depression and/or anxiety, especially where social support is weak (24, 25).

The concept of social support is very broadly defined one but for the purposes of this preliminary report, the essential component of support focuses on the significance of human relationships and some form of helping element. Pearlin et al (1981) described support as '*access to and use of individuals, groups or organizations in dealing with life's vicissitudes*' (26). Support can be in the form of meaningful social contacts, available confidant/s, or human companionship (27). As noted earlier, support is important to people affected by chronic illnesses as the stresses of living with them can increase their vulnerability to depression and anxiety or a more serious form of psychological distress if support isn't available.

7.1 The Importance of Social Support to people with Diabetes and/or CHD and to Health Professionals working with these patients

A diagnosis of a chronic long term condition such as diabetes and/or CHD is a major life event for the individual concerned and families. Life event stresses are associated with acute events or chronic situations that require significant adaptive changes in a person's lifestyle. Wider research on severe life events and peoples' psychological state of mind has shown that having strong support systems can reduce the risk of developing psychological problems such as anxiety and depression when faced with severe events (27).

As noted earlier in this report, the concept of social support involves the provision of emotional support and emotional comforting or a social network which acts as a buffer to the stresses of everyday life. It can range from one to one confiding support from an individual a person feels comfortable about discussing their innermost thoughts and feelings with, support from a social network of people a person feels they have something in common with, and the exchange of information and advice designed to answer important issues in that person's life. The outcome of such interaction is beneficial to the person seeking that support either emotionally through reducing distress and/or improving a person's emotional outlook or by providing a buffer to day - to- day pressures which helps them with day-to-day living, or all three (28).

It is important to note here that research has shown that whilst shared experience is

important when confiding one's personal circumstances, a person doesn't necessarily have to confide with someone in exactly the same circumstances. The benefits of confiding to a trained professional, such as a nurse are equally valuable. It is the process of confiding in someone who understands, empathises and provides unconditional support that has been shown to be valuable (27)

This support is often needed because of the psychosocial impacts of a diagnosis of diabetes and/or CHD. For the purposes of this report, the term psychosocial relates to the psychological and social aspects of people's lives. It covers how a person thinks about themselves and their situation, their emotions and the daily practical aspects of their lives from personal relationships through to day-to-day issues such as employment and managing finances and one's social and personal networks. When a person receives a diagnosis of diabetes and/or CHD, all these areas are affected, not just their own but their family's too.

Despite this recognition, psychosocial aspects can often be missed by healthcare specialists, especially at the beginning of a person's treatment. For example, a study by Farrell et al. (2005) identifying the concerns of 33 women undergoing chemotherapy in Northwest England found that experienced nurses could not identify the majority of patients' concerns and were biased towards physical and treatment related issues. The researchers concluded that their study provided clear evidence for the importance of a continued focus on psychosocial aspects of care during the preparation of staff for clinical roles with patients diagnosed with chronic illnesses. They also believed their findings highlighted the need for preparation in listening and responding to non-medical, psychosocial concerns which touch on aspects of care with which health care professionals may feel less familiar and comfortable.

In the context of what type of support patients in Angus with diabetes and/or CHD said they wanted, this came in a number of different forms. It can be a group form of support such as a diabetes support or cooking or CHD exercise group where people affected by these conditions share experiences with each other, or a more individual one-to-one type of support of sharing or confiding.

These different support forms are usually targeted to one of three points on the illness trajectory: diagnosis/pre-treatment, immediately post-treatment or during extended treatment (28). Certain types of supportive interventions for people affected by diabetes and/or CHD have been shown to be more effective at one or more of these time periods. When Van Dam et al (2005) conducted a systematic review 'Social support in diabetes: a systematic review of controlled intervention studies' (30), they noted that

New forms of social support may be discussed and incorporated in the work of diabetes teams, and offered to patients as new. Diabetes care providers in their daily practice should strive for open communication about social support with their patients. Diabetes teams may consider to offer some of the promising new forms of social support that were found: patient group consultations with diabetes care providers, peer social support group sessions or following diabetes possibilities to help them adjust to a life with (type 2) diabetes and make information-based decisions.

In their review of psychosocial factors and CHD, Bunker et al (2003) noted a strong and consistent evidence across all the reviews that social isolation and lack of quality social support are independent risk factors for CHD onset and prognosis: the risks are increased 2–3-fold and 3–5-fold, respectively. The association exists for both men and women, subjects living in different countries, and various age groups. An association was found in studies that examined some aspect of the size and nature of a person's social network and in studies that examined the type of support received. Ikeda et al (2008) noted that studies conducted in Western countries have found a robust association between social support and cardiovascular outcomes (e.g., prognosis after myocardial infarction and functional recovery after stroke) (27).

7.2 Economic Benefits of Social Support to the Wider Healthcare System

When discussing new ways and directions of tackling the growth of chronic illness in modern society, Walker et al (2003) estimated that effective psychosocial support services lower general health service use by between 7% and 17% among people with chronic illness (28).

Other reviews on the benefits of providing psychosocial support also point to cost savings for the wider healthcare system. Carlson & Bultz (2003) reviewed the literature detailing the extent of psychological distress in cancer patients (increasingly being treated today as a long term condition), the staffing needed to treat such levels of distress, and the effectiveness and value of psychosocial treatments for cancer patients were assessed. From their review they concluded that providing psychosocial support for people affected by long term conditions:

shows large savings in medical billing through the treatment of emotional problems, including anxiety and depression, resulting in fewer visits to GPs and specialists alike. Although there is very little research on psychosocial oncology to date, studies seem to support the general findings in other (LTC) groups of fewer visits to primary care physicians after receiving efficacious psychosocial treatment. Clearly, the time has arrived to promote a compassionate model for treating patients' physical and emotional needs as a vital part of our healthcare systems (29).

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References

1. Davies SJC, Jackson PR, Potokar J, Nutt DJ. Treatment of anxiety and depressive disorders in patients with cardiovascular disease *BMJ* 2004;328:939-943.
2. Barth J, Schumacher M, Herrmann-Lingen C. Depression as a Risk Factor for Mortality in Patients With Coronary Heart Disease: A Meta-analysis. *Psychosomatic Medicine*, 2004;66:802-813.
3. Whooley M Depression and cardiovascular disease: healing the broken-hearted. *JAMA* 2006; 295(24): 2874-81
4. Lin EHB, Katon W, Rutter C et al. Effects of enhanced depression treatment on diabetes self-care. *Ann Fam Med* 2006;4:46-53.
5. Fryers T et al. The distribution of the common mental disorders: social inequalities in Europe. *Clinical Practice and Epidemiology in Mental Health* 2005, 1 (14) 1-14
6. Watt GCM. The inverse care law today. *Lancet* 2002;360:252-4
7. Boardman AP. The general health questionnaire and the detection of emotional disorder by GPs: a replicated study. *Br J Psychiatry* 1987; 151: 373-387.
8. <http://www.pcpoh.bham.ac.uk/primarycare/QOF/PDF/Depression.pdf>
9. Howe A. Detecting psychological distress: can general practitioners improve their own performance? *Br J Gen Pract* 1996; 46: 407-410.
10. Wittchen HU, Kessler RC, Beesdo K, Krause P, Hofler M, Hoyer J. Generalized anxiety and depression in primary care: prevalence, recognition and management. *J Clin Psychiatry* 2002; 63 (Suppl 8): 24-34.
11. Stirling M, Wilson P, McConnachie A. Consultation length, deprivation and identification of psychological distress in general practice. *Br J Gen Pract* 2001; 51: 456-460
- 11b Cameron S, Lawton, K, Reid, C (2009) Appropriateness of antidepressant prescribing: An observational study in a Scottish primary-care setting *British Journal of General Practice*. September, 2009.
- 12a. Scottish Diabetes Survey 2008. Scottish Diabetes Survey Monitoring Group.
- 12b Diabetes Action Plan Scottish Executive 2006
- 13a. Better Coronary Heart Disease and Stroke Care: A Consultation Document (2008). www.scotland.gov.uk/Publications/2008/07/30105717
- 13b Scotland Coronary Heart Disease Statistics Fact sheet 2008/2009. British Heart Foundation Scotland.

- 14 [http://www.isdscotland.org/isd/info3.jsp?pContentID=2449&p_applic=CCC&p_service=Content.show& \)](http://www.isdscotland.org/isd/info3.jsp?pContentID=2449&p_applic=CCC&p_service=Content.show&).
- 15 Vieweg et al. The treatment of depression in patients with coronary heart disease. *Am J Med* 2006;119: 567-573
- 16 Zellweger et al. Coronary artery disease and depression. *European Heart Journal* 2003; 25 (1): 309
- 17 Anderson et al. The prevalence of co-morbid depression in adults with diabetes. *Diabetes Care* 2001; 24(6): 1069-1078
- 18 Katon, W, Von Korff, M, Lin, E, Simon, G, Ludman, E, Russo, J, Ciechanowski, P, Walker, E. and Bush, T. (2004) The pathways study: A randomized trial of collaborative care in patients with diabetes and depression. *Archives of General Psychiatry* 61, 10
- 19 Katon, W, Schoenbaum, M, Unutzer, J, Lin, E, Fan, M, Hunkeler, E and Williams, J (2006) Cost-effectiveness and net benefit of enhanced treatment of depression for older adults with diabetes and depression. *Diabetes Care* 29, 2, 265 – 270.
- 19b. Scottish Executive 2005a, Building a health service fit for the future. A national framework for service change in the NHS Scotland. SE, Edinburgh.
20. Strauss, A. and Corbin, J (1998) Basics of qualitative research (2nd ed). Sage.
21. Scottish Executive 2005b, Delivering for health, SE, Edinburgh.
22. Scottish Executive 2004, NHS Reform Act Scotland, SE, Edinburgh.
24. Champion, L. 1995, "A developmental perspective on social support networks," in Social support and psychiatric disorder, T. S. Brugha, ed.
25. Davison, K. P., Pennebaker, J. W., & Dickerson, S. S. 2000, "Who talks? The social psychology of illness support groups", *American Psychologist*, vol. 55, pp. 205-217.
26. Pearlin, L. I., Menaghan, E. G., Lieberman, M. A., & Mullan, J. T. 1981, "The stress process", *Journal of Health and Social Behavior*, vol. 22, no. 4, pp. 337-356.
27. Ikeda A, et al. (2008) Social support and stroke and coronary heart disease: The JPHC study cohorts II. *Stroke* 39:768–775.
28. Walker, C., Peterson, C. L., Millen, N., & Martin, C. 2003, Chronic illness. New perspectives and new directions Tertiary Press, Croydon.

29. Carlson, L. E. & Bultz, B. D. 2003, "Benefits of psychosocial oncology care: improved quality of life and medical cost offset", *Health and Quality of Life Outcomes*, vol. 1, no. 8.
30. van Dam et al (2005) Social support in diabetes: a systematic review of controlled intervention studies. *Patient Education and Counselling* 59; 1–12.
31. Hipsley- Cox, J et al (1998) Depression as a risk Factor for Ischemic Heart Disease in Men *BMJ* 316:1714-1719.