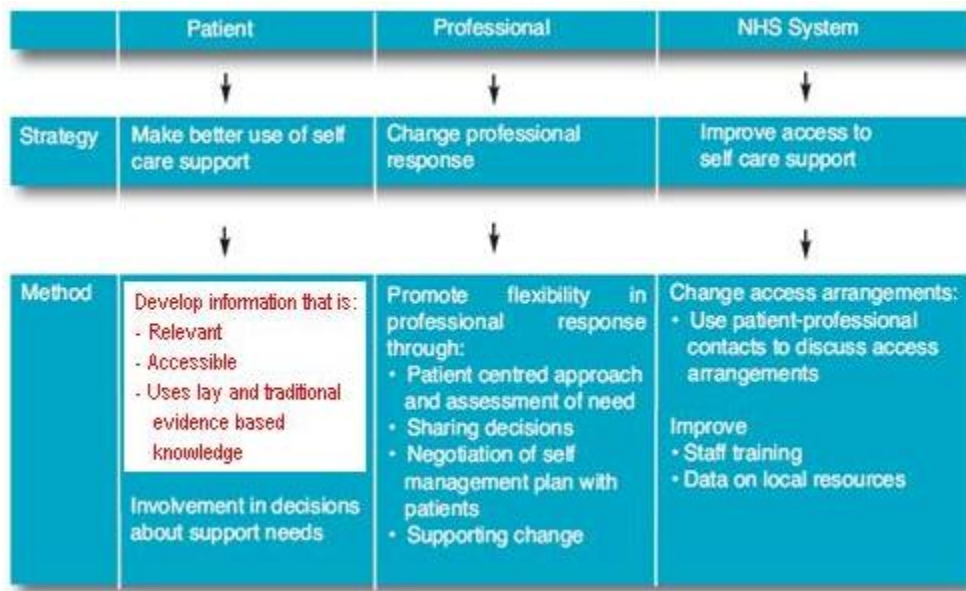


Developing Cartoons in order to Support and Engage people with Long-term Condition Self-Management

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The WISE Approach[1]

In the development of patient centred information described in column 1, cartoons have been used in the self-management guidebook development process. We think that cartoons can be used widely in developing resources and are important for engaging patients with self-management support.

The relevance of humour

Humour is used a great deal in everyday communication and any brief survey of public health and patient information shows that cartoons are often used to amuse or inform through several formats (written, audio-visual or online media).

We know that information on its own has limited or no effect[2]. There has been a focus on making language clearer and more user friendly[3] people with long-term conditions and their carers often use humour as a way of coping with the stresses, anxieties and embarrassments of their lives [4-10]. Cartoons help provide clarity, insight and understanding. Their use in patient information has been shown to be more effective than using text alone[6;11-13].

Cartoons and self-management support

Cartoons accompanying self-management information can be used to address health literacy [14] by:

- imparting humour (which improves recall and understanding of information[11])
- providing resonance with shared experiences (a visual reminder that other people have similar problems and have found solutions)
- communicating complex ideas (cartoon provide a simplified short-cut illustrating ways of dealing with embarrassing situations and things people are reluctant to talk about).

Cartoons can be used to present situations in a non-threatening way and their simplicity can give a clear focus to an idea or thought. Cartoons should be used in a way which is meaningful and not in a counter-productive or disturbing way [11]. Here we describe how lay views and patient experiences were used to develop cartoons in a series of self-management guidebooks. This has been a longitudinal process of learning about reactions to images and what is acceptable. We have developed a process for using the

topics and themes generated through the analysis of the qualitative data to help inspire and create ideas for cartoons. The guidebooks were developed with the following underlying principles:

- **Patients to be included throughout development to allow**
 - Lay informed experiences to be given equal weight to medical and clinical informed evidence;
 - The inclusion of personal experiences and anecdotes to bring the information alive; and
 - Information which is based on patient’s expressed needs and actual ways of managing and not on assumptions.
- **Incorporate good design to aid understanding**
 - Use of plain English; and
 - Use of clear diagrams, pictures and cartoons.
- **The content to include and acknowledge areas of uncertainty or lack of evidence to encourage people to:**
 - Think about how they currently manage their condition;
 - Think about what they want to change; and
 - Plan how to make changes by themselves; using the support of family and friends; or working with their doctor or nurse.

Table 1 outlines the methods and analysis used and the publications relating to the guidebooks.

Table 1 Methods used to develop the guidebooks

Guidebook and study ethics	Main method and analysis	Other methods	Publications related to book development and evaluations
Ulcerative colitis (Published 1999, 2006 (3 rd edition))	Interviews with patients Thematic analysis	Focus group with patients, interviews with clinicians, search of grey literature, search of published literature	[15-23]
Crohn's disease (Published 2000) The project was approved by the North West region multicentre research ethics committee (MREC 98/8/23)	Interviews with patients Thematic analysis	Focus group with patients, interviews with clinicians, search of grey literature, search of published literature	[18-21]
Irritable bowel syndrome (Published 2000, 2009 (2 nd edition)) The study was approved by the Local Research Ethic Committees for Bury & Rochdale (BRLREC57:A), Central Manchester (CEN/99/136), and Salford & Trafford (99150) Health Authorities.	Focus group with patients Thematic analysis	Interviews with patients, search of grey literature, search of published literature	[24;25]
Diabetes (Published 2008) Oldham Local Research Ethics Committee reference: 07/H1011/96	Search of published literature Thematic analysis	Interviews with patients, focus group with nurses, search of grey literature,	[26;27]
COPD (Published 2008) Oldham Local Research Ethics Committee reference: 07/H1011/96	Focus group with patients Thematic analysis	Interviews with patients, focus group with nurses, search of grey literature, search of published literature	[26]
Early stage chronic kidney disease 'Keeping Kidneys Healthy' (Published 2011) North West 7 REC Reference: 10/H1008/1	Focus group with patients Thematic analysis	Interviews with clinicians, search of grey literature, search of published literature	[28]

The interviews and focus groups were recorded, transcribed and analysed. The guidebooks were then developed using the following steps:




- Empirical data to develop themes around patient experience, lay management techniques, and the uncertainties and complexities of living with long-term conditions.
- Use published qualitative literature to help develop themes of patient experience and guide the gathering of useful medical evidence.
- Produce a draft version of the book containing narratives, 'stories' and quotes from patients, basic information about the condition and details of ways to self-manage .
- Review of the draft by patients and specialists.
- **Commission cartoons and photographs.**
- Rewrite and incorporate good design in the layout.
- Trial.

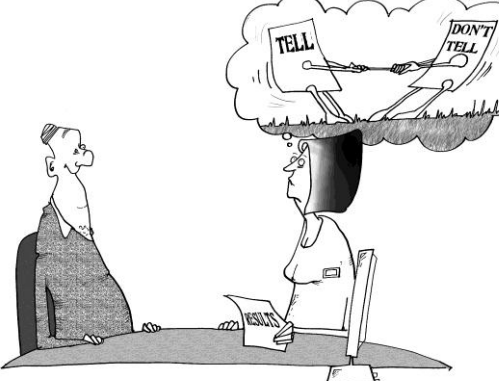
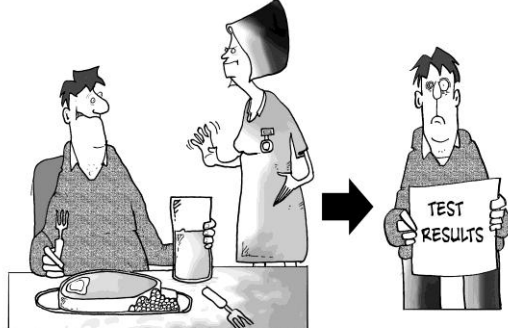
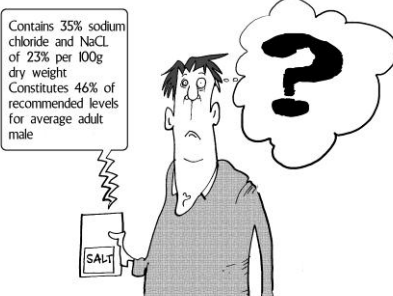
Cartoon development process



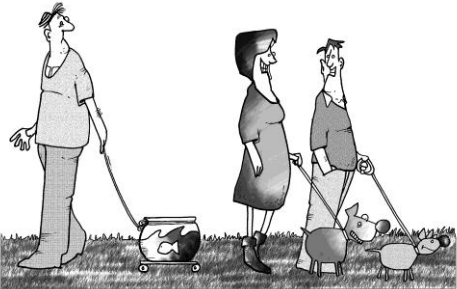
The interviews and discussion groups were used to generate representational quotes about patient practices and experiences that might be illustrated by a cartoon: the experience of living with the condition, common situations, dilemmas of day-to-day management, the opportunities and difficulties of making decisions or choices, or the uncertainties associated with the condition. For each booklet, a list of topics for cartoons was developed and linked to a patient quote. A cartoonist was commissioned and an iterative process in a dialogue with researchers was used to refine the cartoons. An example of a list of topics for the (GM-CLARHCS) early stage chronic kidney disease book is given in table 2 together

with the quotes that generated ideas for cartoons and the cartoons that were finally selected for the guidebook.

Table 2 List of cartoon topics for the chronic kidney disease book

Topic	Quote	Resulting Cartoon
<p>1. Uncertainty about diagnosis because being called into GP practice for so many repeat tests</p>	<p><i>"I didn't know I had a problem because I was having blood tests last year for various things and I had my kidney blood test done about three times"</i></p>	 <p>A cartoon set in a hospital. On the left, a sign reads 'WAITING AREA'. A man is sitting on a roll of fabric, having just pitched a tent. He says, 'I thought it would save time if I just camped here'. On the right, a sign reads 'SURGERY'. A nurse stands there, looking at the man.</p>
<p>2. Something around not doing anything today and storing up problems for the future</p>	<p><i>"I just got a letter telling me about my kidneys weren't right and it's still on my notice board and I said, "No you've got me mixed up with somebody else". He said, "No you've got kidney disease". So I said, "Well where can I go, what can I do, what can I buy, you know?"</i></p>	 <p>A cartoon showing a man in a waiting area. He is holding a coffee cup and looking thoughtful. A thought bubble above him says, 'Hm! Nothing to do today!'. In the background, there is a notice board with several items pinned to it: 'Remember the DOCTORS', 'CALL SURGERY', 'COLLECT PRESCRIPTION', 'NEXT APPOINTMENT?', and 'DON'T FORGET MEDICINE'. There is also a sign for 'DOCTOR APPOINTMENT' and a coffee machine on a counter.</p>
<p>3. The term chronic and different way GP and patient might interpret</p>	<p><i>What do you think about the words chronic kidney disease, what do they make you feel?</i> <i>Person 1: Frightening.</i> <i>Person 2: Well it is frightening because at our age we know chronic as being...</i> <i>Person 3: Hard, bad.</i> <i>Person 4: The end of the road really don't we.</i></p>	 <p>A cartoon showing a doctor and a patient sitting at a desk. The doctor is looking at a document and says, 'Something we need to keep an eye on!'. The patient is looking thoughtful. A thought bubble above the patient shows a cross with the word 'CHRONIC' written on it.</p>

	<p><i>Person 5: Chronic is, you know, you're critical, sort of, really, you're at a stage where, you know, things can go vastly wrong</i></p>	
<p>4. GP judging time not right to tell them about yet another condition</p>	<p><i>"No I don't want too much knowledge, you know, really, so the GP has to judge it if he knows his patient then he has to judge whether to tell them or not."</i></p>	
<p>5. What not to do before blood test</p>	<p><i>Suggestion from a nurse</i></p>	
<p>6. Salt as bad or vital part of diet</p>	<p><i>"I think we really need a diet sheet... don't do that or cut right down on them, you know. That would be very helpful if they have a list of things; do and don'ts"</i></p>	

<p>7. Making family decisions about meals and shopping</p>	<p><i>“Some people it would really be a problem for them to not have biscuits but it doesn’t bother me and we’ve always eaten fresh food so, you know, just a healthy diet really and that’s what we do.”</i></p>	 <p>A cartoon illustration. On the left, a man stands at a counter with a sign that says 'SALAD'. He is holding a tomato. On the right, a child is carrying a tall stack of four pizzas, each labeled 'PIZZA'.</p>
<p>8. Making alternate exercise plans when things don’t work out</p>	<p><i>“We used to go swimming and sauna, the sauna closed and then the baths closed for a while. So from that, certain friends who I used...there was a nice group of us went to the gym that you pay an annual membership whatever. I didn’t want to do that, I didn’t want to be tied to be going two or three times a week to get your money’s worth out of it. When it’s decent weather I’d sooner go for a walk then go to a gym...”</i></p>	 <p>A cartoon illustration. A man with a large, bulky backpack and a hat is talking to a woman sitting in a chair. A speech bubble from the man says: "The pool was closed so I thought I might climb the North face of Everest instead...".</p>
<p>9. Exercise motivation - How dog-walking introduces you to others</p>	<p><i>“Now, I do a lot of exercise, unfortunately, I’m on my own, single, I’ve a dog, so we walk about four hours a day.... You meet lots of people that way as well, who have diabetes and other illnesses and get to know things, what’s happening...”</i></p>	 <p>A cartoon illustration. Three people are walking their dogs on leashes in a grassy area. From left to right: a man with a dog, a woman with a dog, and a man with a dog.</p>

This section uses the cartoons plus accompanying quotes to illustrate the process.

Experiences

There were differences in the types of reactions according to the condition. For example, for people with COPD, which is a progressive disease strongly associated with smoking, common emotions were the negative reactions of guilt and loss. Patients often suffer shame and guilt over what is perceived as a self-inflicted disease[29] and this can lead to avoidance of discussions and behaviours such as escaping to the toilet to use an inhaler (see figure 2). People with COPD describe a continuing and progressing sense of decreasing ability to take part in pleasurable activities, they talk about learning to shift from being active to being sedentary and how this impacts on their social lives[30]. (See figure 3)

Figure 2: Guilty use of inhaler in COPD



When I was still working I used to take the puffer to work but I used to go in the toilet and do it

Figure 3: Decreasing abilities in COPD



For people with diabetes, experiences suggested feelings of loss of control and that health professionals in particular were making moral judgments on them as ‘bad’ patients. The loss of control was connected to experiences of family and friends feeling compelled to make decisions about food on their behalf[31]. (See figure 4) Diabetes discourses bring out concerns about how other people judge and view behavior and outcomes related to the condition[32]. (See figure 5)

Figure 4: Loss of control in diabetes



Figure 5: Moral judgements in diabetes



I told her everything. That I'd been bad. I wasn't looking forward to going in you know...and she's taken my bloods and I know it's going to be high, so I'll be told off when I go back you know

For those with the early stages of kidney problems, experiences were of anxiety and uncertainty because the diagnosis was not linked to symptoms but was found as a result of blood tests. The terminology used by health professionals generated anxiety with people thinking they were heading for kidney dialysis or early death when they heard or read the words 'chronic kidney disease' (see topic 3 in table 2).

Common situations

Interviews and discussions in focus groups indicated that certain aspects of life with a long-term condition meant that people wanted to avoid being alone in what they went through or in the methods they found to cope. People who had IBS often spoke about having a detailed knowledge of where accessible toilets could be found and planning their outings around these mental maps (see figure 6).

Figure 6: Planning outings in IBS



Dilemmas of day-to-day management

A great many of the day-to-day problems emerge from trying to fit a more restrictive diet into everyday domestic life, such as the decisions that have to be made about shopping and meals. For many people life is a continual challenge of having to work out and prioritise individual needs against familial needs[33]. (See figure 7)

Figure 7: Family meal challenges in diabetes



The biggest challenge is being in the house. I mean I've still got family living here so I have to provide things that they like as well. So I still - and I mean I haven't ever avoided it buying biscuits and things and that in the house I've always had them in.

Making decisions and choices

Having a long-term condition can mean struggling with decisions about actions and continually having to weigh up the balance between the immediate benefits of pleasurable social activities and the impact on your future health which can be hard to maintain on a day-to-day basis (see figure 8). One solution that people come up with in order to achieve a more balanced and normal life is to maintain a sense of wellbeing through 'strategic cheating'.

Figure 8: Maintaining a balance between health and social needs

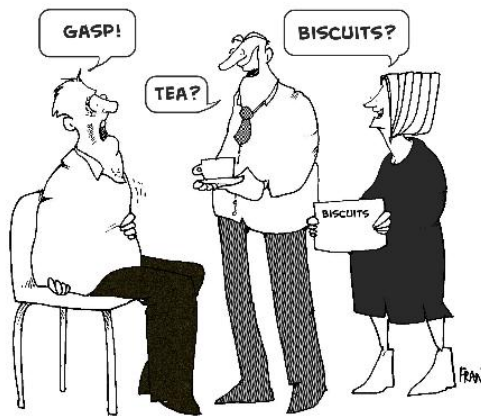


Most of the time, we want to act and be like other people. Most social activities involve eating and drinking and feeling that you always have to think about the effect on your diabetes can be frustrating and make you feel like a bit of a social misfit.

Uncertainties associated with conditions

Uncertainties and confusions can happen at any stage in managing long-term conditions. Some of the uncertainties are to do with how other people view you and how to deal with well-meaning help when you develop unwanted symptoms, for example when people with COPD suddenly have breathing problems (see figure 9).

Figure 9: Having to deal with well-meaning but unhelpful advice in COPD



A lot of people when you're coughing and struggling say do you want a drink and you say ... I feel like saying a drink's of no value at all because if you poured a drink down me lungs you're going to drown me. And they say oh alright. When I've really been bad the people that are looking after you become very apprehensive and then you become apprehensive because they know you know they can't do anything for you. So I'll tell people all I want you to do is be there for me in case I need you.

Discussion

The development and dissemination of written information is insufficient to meet patient needs which are complex and multi-faceted in the area of long-term conditions. We have developed resources taking note of the way in which information is delivered and received and uses the personal resources of those affected by a long term condition. The personal resources of patients are assets that require nurturance, development and expression [14] and can be used to support mundane as well as complex

health decision-making . The later evidence has been a feature of the development of resources discussed in this paper[34].

The inclusion of bespoke cartoons based on experiential, lay knowledge and narratives together with making use of metaphor and humour, known agents of engagement in health matters, is one means of addressing health literacy and self-management support in the arena of long-term condition management. The standardised process we developed to create meaningful cartoons to accompany and enhance the delivery, sharing and embossing of patient information, has meant the cartoons have been well-received by patients and clinicians. The development process has been based on evidence about the relevance and salience of lay knowledge (as well as clinical knowledge) for patients [3] and the acceptability and utility of using the guidebooks in practice in a global sense (see table 1).

We consider the use of humour and cartoons engages and motivates people with self-management and improves the narrative elements and tailoring of information to support self-management.

The specific impact of the cartoons themselves are currently being evaluated by using qualitative methods in a study involving the kidney disease booklet.

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