

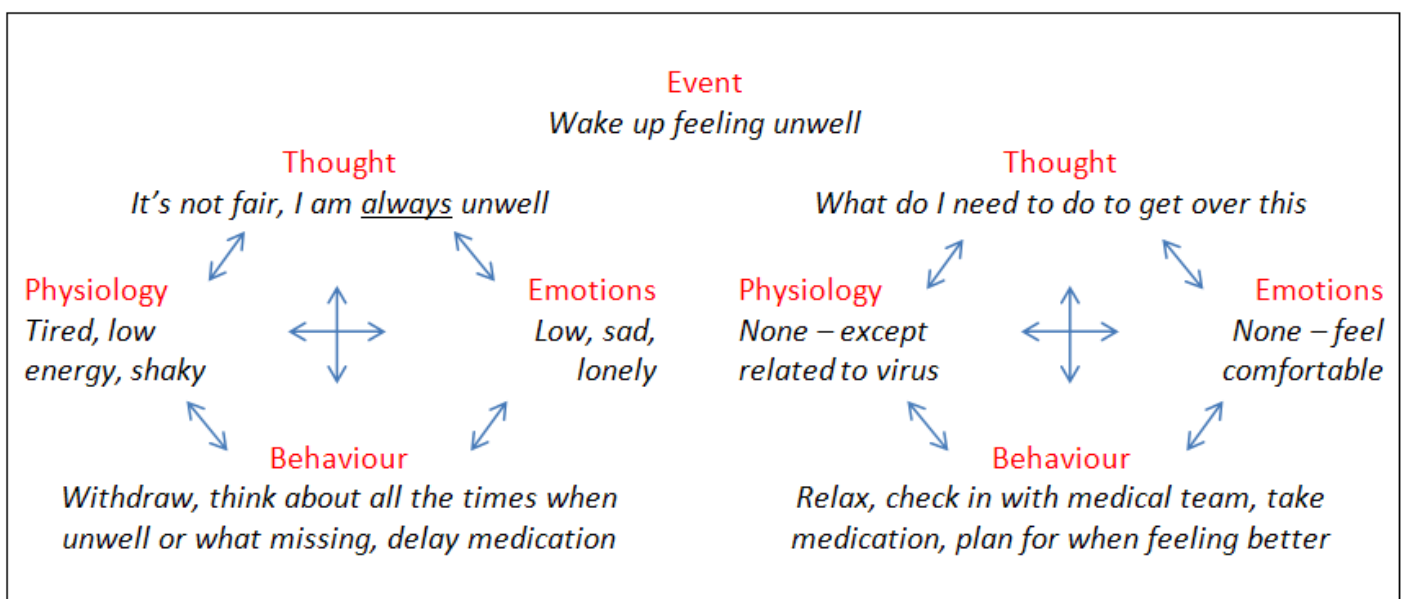
The Role of Cognitive Behavioural Therapy in the Management of Primary Antibody Deficiencies (PADs)

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What is CBT?

Physical health and mental well-being are linked. Whilst the majority of people with long-term conditions generally manage well, at times physical illness can have a negative impact on people’s quality of life (Department of Health, 2008). The National Institute for Clinical Excellence (2009) found that adults with chronic illnesses are at increased risk of suffering from depression when compared to the general population, and we also know that poor mental health can affect an individual’s ability to manage their physical health. However, it is not always the most ill who are most affected by their condition, suggesting that many people develop their own skills to help them through physical disability.

Cognitive behavioural therapy, or CBT, is a talking treatment that helps individuals learn how to identify and challenge some unhelpful patterns of thinking (cognitions) and behaviour. Take the example in the panel below – when waking up feeling unwell, the individual on the left had the thought that it was unfair that she was always unwell. This made her feel sad, low and lonely, and also pretty rubbish physically. As a result she withdrew from friends and family, reminded herself of the times when she had been unwell in the past or what she was missing out on now, and delayed her medication, which probably didn’t make her feel much better in the long term and the illness took longer to resolve. However, the person on the right was different; she started to think what she needed to do to overcome her illness and put those plans into action, along with doing things that she enjoyed whilst she was recovering. Consequently, she did not feel any negative emotions or physical distress due to the difficult feelings.



CBT supports individuals to develop and enhance skills and techniques that can help them out of negative cycles of thoughts and behaviours and into more helpful or adaptive patterns. Treatment encourages individuals to talk about how they think about themselves, the world and other people,

as well as thinking about how what you do affects your thoughts and feelings. Well established as the treatment of choice for a variety of mental health difficulties (e.g., anxiety, depression, panic and phobias), CBT has also been shown to be helpful in managing symptoms of long-term conditions such as diabetes, COPD, pain and chronic fatigue (British Pain Society, 2007; Kissel & Clouse, 1997; Kunik et al., 2001; NICE, 2007).

Relevance to PID patients

Professionals managing people with Primary Antibody Deficiency (PAD) have long been aware of the impact the illness has on the individual's general life. Although in its infancy, the research suggests that some adults with PAD have higher levels of anxiety and depression, and a poorer quality of life when compared to the general population. In addition, it seems that some factors known to impact negatively on quality of life could be improved through cognitive-behavioural techniques.

The Royal Free Psychology Service

Through funding from the Primary Immunodeficiency Association, the Royal Free Special Trustees Fund and the Royal Free Charity, the Department of Clinical Immunology has been able to set up a hospital based psychology service for PAD patients. This has been running for nearly two years, offering short-term, time-limited CBT to suitable patients selected through discussion with the medical team or on the basis of the results of a short questionnaire designed to identify those likely to benefit. Eighty eight patients have been offered an assessment and 63 have attended for their first appointment. To date, forty-eight people have started a course of treatment. The expectations of those using the service vary and include improvements in mood, general anxiety, specific health anxiety, insomnia and fatigue. Sessions have also been used to reflect on the impact the illness has on their own and other's lives, for example on their relationships with family and friends, career or educational aspirations, sexual functioning, travel plans, as well as thinking of different coping strategies to help them lessen this impact. So that we can convince people that CBT is useful, we designed a scientifically valid scoring system to measure improvements after treatment.

Outcomes

Patients who have completed a CBT course report high satisfaction with the model and service, spending more hours outside of the house per week, fewer days when they were unable to fulfil household tasks and a reduction in the number of days taken off work for medical appointments. They also report statistically significant improvements in their mood, sleep and energy levels, and decreased levels of anxiety. With regards to medication, patients appear to make better use of prophylactic antibiotics after CBT, while taking less additional courses of antibiotics. Frequency of out-patient appointments, in-patient days and A&E visits are also reduced, while GP appointments and contacts with the RFH clinic increase. This suggests a better understanding of medical treatment and advice, and how this can fit into a patient's own everyday life, which in turn can lead to a more appropriate use of medical resources.

The future

The psychology service is also being evaluated scientifically and the results of this project are currently being prepared for publication. By emphasising the overall cost benefit to the NHS, and the potential for improving quality of life, we hope that the new NHS commissioners will recommend that a psychologist should be included in all clinical teams caring for PID patients. Over the next few years we hope to expand the service to all types of PID, as well as engage with you, the Primary Immunodeficiency Patient Group, to develop a treatment model that highlights the importance of putting the patient at the centre of care, so that this can be used throughout the UK.