

You need to be able to work with your doctor(s) to develop an understanding of the way in which your condition affects you: this will help you to cope with bizarre symptoms and pain that relates to the condition but could otherwise be interpreted as signalling a serious, undiscovered condition such as cancer.

General information about benefits, financial matters; logistical issues (disabled access to shops/on holiday, for example) can be enormously helpful.

Partners and family also need to have access to information so that they can have their fears and concerns addressed and also that they have the opportunity to give you the appropriate support.