

REACTIONS FOLLOWING DIAGNOSIS CHRONIC KIDNEY DISEASE



REACTIONS FOLLOWING DIAGNOSIS

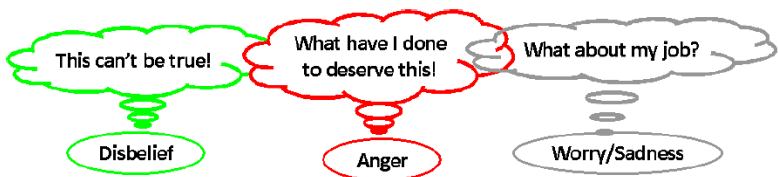
A diagnosis of Chronic Kidney Disease (CKD) or any ill health is going to be a shock to the individual and their family, resulting in a state of numbness. This may last a few minutes, days, weeks or months. This reaction is similar to the experience of grief, a feeling of loss, i.e. loss of good health. For some people it may come as a relief as they now have a diagnosis for their symptoms.

Individual reactions can be very different from person to person, but, all involved will at some point come to realise the need to accept change or transition in some form. These changes may be short or long term, you are no longer the same person following diagnosis or you may be able to carry on life as usual without further interventions. Future changes may take the form of dietary alterations or the addition of medication to your daily routine.

The challenge is for you to accept the diagnosis of CKD and identify what this means for you and your family; working through your thoughts and feelings – similar to that of grieving for a loved one. You will be required to educate yourself about CKD, and consider the impact not only on yourself but your family too.

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This in turn will have consequences for you and your family to overcome. Initially you may find it difficult to do anything because of the feeling of shock. However, this does pass and you will be finding yourself possibly trying to minimise the consequences or effects on yourself and others. Or you are able to adjust to letting go of the past, and start incorporating changes, testing future possibilities and finding some meaning in the experience for yourself and your family. Not everyone moves through this at the same pace nor takes the same path. You may find yourself repeating or returning to different tasks or challenges many times throughout this process of adjustment and change.



Reactions following diagnosis : examples of feelings & thoughts

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ADJUSTMENT AND CHANGE

IS YOUR REACTION TO THE NEWS OF CKD COMMON?

Any reaction such as confusion, denial, anger, sadness, disbelief, guilt, shame, isolation, or frustration is common. It is how you deal with these feelings and thoughts that are unique to you. You come to this new information regarding your health with a past that has involved many challenges and you will be required to use some of those strengths, resources and skills to help you cope with the life changing news of CKD. Or you may be required to develop new ways of coping.

HOW DO YOU VIEW THE INTRUSION OF "ILLNESS" TO YOUR LIFE?

Are you viewing a diagnosis of CKD negatively or positively, i.e. end of your life or new challenge to overcome? How you react to the news of CKD will determine your thinking, behavior and feelings now and in the future.

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WHAT IS THE WAY FORWARD?

Think positively about this diagnosis and impending change. View it as yet another of life's challenges. If you are able to work towards letting go of the past, moving forward will help you to feel more in control of your life and situation.

ARE YOU HAVING TROUBLE SLEPPING PRIOR TO A KIDNEY CLINIC APPOINTMENT?

- You may be worrying about what the doctor or nurse is going to say; whether your blood results have worsened requiring changes to your diet or medication; or needing further tests or procedures
- You may experience anxiety or panic about having your blood taken
- You may not like going to hospital
- You worry about the future and whether you will be able to continue to e.g. work.

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WHAT CAN YOU DO TO HELP YOURSELF FROM WORRYING ABOUT APPOINTMENTS?

- Come prepared to appointments with questions to ask
- Involve yourself in finding out about your blood tests and write them down at each clinic visit
- Follow recommended advice and treatments (medication, diet)
- Talk to family, friends, nurse or doctor about your concerns or worries
- Speak to the nurse or doctor about being referred to a counsellor to help manage your anxiety, panic attacks or phobias.

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HOW DO YOU SWITCH OFF FROM YOUR THOUGHTS OF “WHAT IF...”?

You may find yourself worrying about the future – what if this or that happens? It is important to challenge these thoughts – what is possibly likely to happen and what is more probably going to happen? Discuss these with your nurse or doctor. Write these thoughts down so that when you attend your kidney clinic appointments you can remember what questions were worrying you.

ARE YOU FEELING OVERWHELMED?

By giving attention to how you feel and talking with family, friends, nurse and/or doctor will help you to manage your feelings in relation to the news of CKD.

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WHAT CAN YOU DO TO HELP YOURSELF?

Some people keep a diary and write down their thoughts and feelings as a way of working through the information. Others find talking helps – whether this is with family or a trained counsellor, psychologist or social worker. Whatever you do, do not keep your feelings and emotions from being expressed. Suppressed feelings will manifest themselves in the future – either through anxiety, depression or bodily symptoms, e.g. difficulty sleeping, panic attacks. So, find a way to express or expend the emotional energy you are feeling, e.g. exercise, sport, meet up with a friend(s).

DO YOU FEEL ALONE AND ISOLATED?

It is common to feel like this and to feel you are the only one with CKD. You may feel like no-one understands how you are feeling or what you are thinking. This is true unless you speak to others and let them know this is what is concerning you. Family members too, often feel alone and isolated because they do not know how to help you, especially when the person directly affected by CKD does not communicate with them. So speak to family and friends and if not them, then your doctor, nurse, renal counsellor/psychologist or social worker at your clinic. You do not have to go through this process on your own.

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WHAT MIGHT BE WORRYING YOU ABOUT POSSIBLE FUTURE CHANGES?

- “Can I continue working?” – as long as your symptoms are not interfering with your activities of daily living you will be able to continue working. However, you will need to monitor this on an individual basis. For example, if you are working at a manual job you may find you become more tired as opposed to someone who sits in an office.
- “Will my employer need to know about my diagnosis?” – having as many people aware of your health concerns as possible allows you to have different people to discuss your concerns with. If you feel your employer will be sympathetic – tell them, especially if you are required to attend the hospital for more frequent appointments and or tests. You will need time off or some flexibility in your work hours, therefore if they know, they can support you.

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FUTURE RELATIONSHIPS

- “What do I say to a new partner?” - Be as open and honest as you can about your kidneys. Pick your time to tell the person when you have privacy and the time to talk. Leave information leaflets; appointment letters lying about to initiate a conversation on the topic. Invite him or her along to your appointments – involve him or her in the process.
- “Can I still have sexual relations?” – Sometimes medication, certain health conditions, stress, anxiety and depression may affect your libido and ability to perform sexually (getting or keeping an erection). Again, being as open and honest with your partner about your condition and how it affects you can in turn lead to discussions about being inventive and creative together.

Speak to your GP or kidney clinic doctor about any concerns you may have regarding sex – they will be able to help, offer interventions for you, or refer you on for investigations if it is a mechanical problem. If it is a psychological issue they could refer you to a counsellor or psychologist with your permission.

For those unable to perform penetrative sex, do not forget you can have a meaningful relationship in other ways, e.g.cuddling, kissing, stroking, massage.

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Do not isolate yourself or your partner – keep communication open and honest.

STRESS

WHY ARE YOUR MOODS CHANGING?

- Stress is a normal response to life events that threaten or upset the balance. It is our bodies' way of protecting us - "flight or fight" response. When stress is manageable it helps us to stay focused, energetic and alert. However, when we become overwhelmed it can damage our health, mood, relationships and our overall quality of life.
- Grief affects people in a variety of ways and you have experienced a loss. So there is no surprise that you will have 'good days and bad days'.

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WHAT ARE THE SIGNS AND SYMPTOMS OF STRESS?

- Cognitive - memory and or concentration problems; anxious or racing thoughts; constant worrying
- Physical - chest pain or rapid heart-beat; aches and pains, loss of sex drive
- Behavioural - eating more or less, sleeping more or less; isolating yourself
- Emotional – moodiness; feeling overwhelmed; unable to relax; being irritable or aggressive.

WHAT WILL HELP YOU TO TAKE CONTROL OF YOUR STRESS?

Change your thinking, behaviour, reaction to situation, environment. You could speak to a counsellor, psychologist or social worker about your concerns (see depression).

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ASK YOURSELF: "WHAT HELPS ME TO RELAX?"

FOR EXAMPLE:

- Take a bath
- Meet a friend
- Relaxation, breathing or meditation exercises
- Time out, holidays
- Exercise – walk, swimming, cycling, gym workout
- Think of something that you enjoy doing – that is not harmful to you and do it.

DEPRESSION

WHAT IS DEPRESSION?

Depression varies from person to person but there are common signs and symptoms. It is also important to remember that these symptoms (some) are commonly experienced by those with a diagnosis of CKD as well as being part of life's normal low mood. However, if your daily life is effected either mildly, significantly or it is impossible to carry out normal activities of daily living (e.g. work, socialise), you may be experiencing depression. The more symptoms you have, the stronger they are and the longer you have them for are indicative of depression.

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WHAT ARE THE SIGNS OF DEPRESSION?

- Feeling empty and or despair
- Feelings of low self esteem - hopeless or helpless
- Disturbed sleep - difficulty falling asleep and waking early
- No or very little motivation to get out of bed, go to work – “what is the point?”
- You are more aggressive, angry, short-tempered than normal
- Loss of appetite, with weight loss or can't stop eating
- Difficulty concentrating
- Unexplained aches and pains
- You are unable to stop your negative thoughts
- Reckless behaviour – you indulge in escapist behaviour (e.g. gambling, substance misuse, dangerous driving)
- You have thoughts that life is not worth living or thoughts of suicide (seek immediate help).

If you are experiencing some of the above over a two-week period, every day for most of the day please talk to a counsellor, psychologist, nurse, doctor or your GP.

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HOW CAN YOU HELP YOURSELF IF YOU ARE DEPRESSED?

- Talk to family and friends, ask for their support – arrange to meet up and go out
- Eat regularly and well – even if it means forcing yourself to eat
- Avoid alcohol and drugs
- Exercise – walking, gym, yoga, pilates, swimming, stretching in your chair
- Listen to music that is uplifting to you - dance
- Develop a new hobby or interest, something you do not normally do
- Positive self talk – say to yourself “I can do this”
- Set realistic goals – for the morning, afternoon, day. Break it down to manageable pieces
- Write down or draw your thoughts and feelings
- Visualise yourself in the future when these feelings have all passed – what do you see, hear, smell, taste and visualise yourself doing it
- Talk to your GP, kidney clinic doctor, nurse, counsellor or psychologist about your symptoms, thoughts and feelings
- Seek Counselling.

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In spite of how you are feeling, do things anyway. Ask yourself what you enjoy doing and do it. When we're depressed, we can feel particularly tired and lack any motivation to do anything. Just increasing your activity and exercise levels can help to change your mood as it stimulates the body to produce natural anti depressants.

WHAT IS COUNSELLING?

It is an opportunity to speak to a trained professional in confidence about a particular concern or issue you may have in relation to e.g. your health, wellbeing, relationship or social situation. Anything you say to the counsellor, psychologist or social worker is between yourself and them i.e. confidential, unless they have your permission to speak to your doctor or nurse. The relationship is predominantly one sided – you will be doing the majority of the talking – they will be mainly listening to you. Intermittently asking questions that will help you to explore and reflect on information you have spoken about. They can also work with you in teaching you alternative coping strategies i.e. relaxation techniques, changing thinking or behaviour patterns.

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ARE YOU WEAK OR GOING MAD IF YOU HAVE OR NEED COUNSELLING?

No, you are neither of these. At different times you will not be able to live your life as you normally would do, for example in times of increased stress, anxiety or depression. It may be too much for you to carry alone or even with the support of your family and friends. A counsellor or psychologist is trained to listen and most people do experience some relief when they are able to talk about what is worrying them. The counselling experience can only make you stronger as it will demonstrate to you what your limitations are and what areas are in need of strengthening. Sometimes our old coping methods are not always helpful in the present, for example starving or bingeing on food. Then we need to develop new strategies to cope. These can be discussed with the counsellor or psychologist and practised between sessions. A helpful website offering advice and information for managing anxiety, depression, stress and other issues visit:
www.getselfhelp.co.uk

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HELPFUL WEBSITES AND CONTACT DETAILS (UK ONLY):

- <http://www.britishkidney-pa.co.uk>
Counsellor / Support worker Jacqueline Fraser (for units with no counselling service)
Email: jacqueline.fraser@britishkidney-pa.co.uk
Phone: 01420 541424 (support phone line)
- Check out the www.gov.uk website for information on benefits
- Call the Benefit helpline 0800 882200
- National Kidney Federation website: www.kidney.org.uk

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KEY POINTS TO REMEMBER

- You are not on your own – support, information and help is available
- Talk as openly and honestly as you can to your family, friends and kidney clinic nurse or doctor. If they know how you are feeling and coping they will be able to support you by giving you information and advice as you require
- If you are feeling stressed – take some time out to distract yourself; make some changes in your daily life to decrease the tension
- If you are experiencing anxiety or depression – speak to someone – get help
- Think Positively – “I can do this!”
- Let go of the past and look to the future
- Accept change is inevitable
- Find out if kidney clinic or unit has a social worker, counsellor or psychologist offering a counselling service and speak to them
- For those clinics or units that do not have a counselling service contact your local and national kidney organisation or charities for information, advice, support or counselling.

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Text: Amanda Bevin, RN RMN Dip Psyc - UK.

Review: Karen Jenkins, RN, PG Dip HE, MSc Health and Social Care (Nursing) - UK,
Lesley Bennett, RN, RM, BA, MSc - UK

Illustration: Miquel Àngel Velasco Martín, PhD (Cotemporary History), Watercolourist. Barcelona, Catalunya – Spain (renal patient).