KidneyCare
Me and My thoughts
Handling the stress

We all have stress in our lives – at work, in the traffic and at home. Having a chronic condition adds a lot to that stress. You may be worried about your condition and treatments, and worried about what the future holds and how you are going to cope. It is not unusual or abnormal to feel worried, anxious or depressed. The important thing is that you do not ignore those feelings or live with them without seeking help.

Get enough sleep

Experts recommend you get seven to eight hours worth of quality sleep every night.

Practise and use relaxation and stress management exercises

Sitting quietly, listening to music and reading can all help you to relax. There are other specific stress management techniques, including deep breathing, meditation, visualisation, self hypnosis and muscle relaxation. If you are interested in learning more about these techniques, there are various books available at the library or in the book shop and information on the internet. Alternatively, ask your healthcare provider or social worker to send you to someone who can explain more to you.

Your friends and family

Don’t keep your feelings to yourself. Tell your family how you’re feeling. They’re probably also sharing some of the emotions that you are feeling. By talking about how you feel and what is worrying you can help to get things into the open. It helps to show everyone where they can help each other. This helps to avoid any conflict or misunderstandings and to find solutions to challenges.

My support system

Share the load. Connect with others by talking openly to family, friends, support group members or professional counsellors.

Your healthcare providers

You have a network of healthcare providers who can explain your condition and treatments to you. If you are feeling very depressed or worried they can also refer you to other professionals and counsellors who can help you through the difficult times and help you to develop skills to cope better.

My emotional and mental needs

Handling the stress

We all have stress in our lives – at work, in the traffic and at home. Having a chronic condition adds a lot to that stress. You may be worried about your condition and treatments, and worried about what the future holds and how you are going to cope. It is not unusual or abnormal to feel worried, anxious or depressed. The important thing is that you do not ignore those feelings or live with them without seeking help.

Get enough sleep

Experts recommend you get seven to eight hours worth of quality sleep every night.

Practise and use relaxation and stress management exercises

Sitting quietly, listening to music and reading can all help you to relax. There are other specific stress management techniques, including deep breathing, meditation, visualisation, self hypnosis and muscle relaxation. If you are interested in learning more about these techniques, there are various books available at the library or in the book shop and information on the internet. Alternatively, ask your healthcare provider or social worker to send you to someone who can explain more to you.

Your friends and family

Don’t keep your feelings to yourself. Tell your family how you’re feeling. They’re probably also sharing some of the emotions that you are feeling. By talking about how you feel and what is worrying you can help to get things into the open. It helps to show everyone where they can help each other. This helps to avoid any conflict or misunderstandings and to find solutions to challenges.

"You don’t have to do this alone."
Keeping busy

There are times when you will not feel up to doing things. However, doing a work activity, sport or hobby, especially if it involves interaction with other people, can help you to stay positive and motivated.

Fill up your diary. Keeping busy will help you feel focused, purposeful and motivated. But plan carefully. Only choose activities that you feel able to manage comfortably.

Prioritise by doing the most important tasks first, so you can fit in your treatments and necessary everyday tasks.

Learning more about my condition

The more you understand about your condition, the better able you will be to look after yourself, feel the best that you can, and avoid unexpected surprises. You need to understand your treatments, what you can and cannot eat and drink, and what support structures are available to you.

Use trusted and honest sources of information to find out more about kidney failure, dialysis, transplant and answer any questions you have.

Knowledge can be very empowering, and help you take control of your treatment.

Eating healthily

Follow your diet plan. Eating the wrong foods can make you feel unwell and may be dangerous to your health. Avoid alcohol.

---

Support groups

Getting together with people who are going through the same experiences as you are, and understanding how you feel, can be a great support and source of advice and inspiration. Ask your healthcare provider to send you to a support group, or talk to some of the other patients at the clinic. Perhaps you can form your own group of friends who meet regularly.

“Support groups are a crucial foundation for patients and their loved ones coping with a life changing condition like chronic kidney disease,” says Leonie Ackerman of the National Renal Care (NRC).

“Support groups allow those who share a common diagnosis to come together and share ideas, coping tips, and experiences, and most importantly, to exchange emotional support. Most support groups are facilitated by leaders who have personal experience with the disease and who have become advocates for others. The primary goal of most groups is to ensure that no one living with the disease or condition that the group serves ever has to feel alone again,” says Leonie.

In addition to providing important emotional support, support groups also serve as educators, disseminators of news about important advancements or therapies, and advocates on your behalf.

Call for help

The South African Depression and Anxiety Group (SADAG) offers telephone counselling every day of the year, and can also send you to a professional therapist in your area, or give you the details of organisations that offer help and support groups, counselling centres and information.

SMS: 31393
Call: 0800 70 80 90/ 0800 20 50 26 (toll-free, 8:00 to 20:00, seven days a week)
Visit: www.sadag.co.za

---
Toddlers and chronic kidney disease

Toddlers (children between the ages of one and three) are beginning to develop trust and an overall sense of security. Illness can interrupt this and may leave them feeling anxious and angry because their parents do not make the illness disappear. This may show itself in aggressive behaviour.

Toddlers generally have very little understanding of their condition. They experience pain, limitation of motion, and separation from parents as challenges to developing trust and security.

Parents can help by being there for painful procedures, staying with their children (when possible) during hospitalisations, holding, soothing and interacting with their toddler as much as possible.

Pre-school children and chronic kidney disease

Pre-school children are beginning to develop a sense of independence. They may understand what it means to get sick, but they may not understand the cause and nature of the condition. For example, they may believe that throwing up causes them to get sick, rather than the other way around.

Being in the hospital or getting used to medicine schedules can challenge the child’s developing independence. The child may try to stop losing control over their life by testing boundaries set by their parents.

Setting well-defined boundaries is important to help the child. Being firm with things the child does not have a choice over. Never ask: “Do you want to take your medicine now?”, because almost all children will say: “NO!” Rather offer choices, for example: “Which do you want to take first, the pink medicine or the purple?” or “Do you want to sit on my lap while you have your blood drawn or in the chair with me holding your hand?”

Children living with chronic kidney disease

Children are in their formative years and therefore quite vulnerable to how they will see, think and react to the typical loss and limitations kidney failure brings. This makes the role of parents and caregivers important in giving guidance and helping to protect the child from stress.

Children with kidney failure will experience more frequent doctor and hospital visits. Some of their treatments may be scary or painful and hospital stays can be frightening and lonely. They may feel “different” because their activities may be limited and their families often have to change how they live to accommodate the child. This in itself creates stress for the parents, family and caregivers.

The way children react to the diagnosis of kidney failure depends on several factors, including the child’s personality, the extent of the kidney failure, and their family. One big factor is the child’s developmental stage. Children’s understanding of illness and their coping strategies change as they grow older. That is why it is important that parents know and understand these developmental stages (stages a child goes through as they grow up) to be able to deal with their child’s mental reactions to their condition.

Dialysis isn’t easy for anyone, but children particularly find it difficult to cope with the trouble of constant treatments, differences in how they look, as well as limits in the things they can eat, how much outdoor activity they can do, and having to be more careful in every aspect of their lives. It’s really hard to be different to other kids.

“It’s important to teach our children to have confidence in themselves as well as give them crucial coping mechanisms to deal with adversity, whatever the situation,” says Cassey Chambers from the South African Depression and Anxiety Group (SADAG).

“Always encourage your child to speak about his or her feelings,” she advises.

Mothers of children on dialysis suggest trying to keep as normal a routine as possible, and create a happy, healthy environment for your child. It helps too if the rest of the family is supportive in their dietary choices, this can help reduce feelings of being deprived or excluded.

“It’s important to teach our children to have confidence in themselves as well as give them crucial coping mechanisms to deal with adversity, whatever the situation.”
Six and seven year-old children and chronic kidney disease

Children in this age group are developing a sense of mastery over their environment. They can describe reasons for illness, but these reasons may not be totally logical. Six and seven year-olds often have magical thinking and they bring this in to their reality. They may believe they caused their condition by thinking bad thoughts, hitting their brother, or by not eating their vegetables.

Parents can help by allowing their children to help in the management of their condition (with close adult control). They should also reassure their children that the condition is not their fault. Support and reassurance are very important.

Eight to twelve year-old children and chronic kidney disease

This age group is quite mixed in terms of development but generally they are more capable of understanding their condition and its treatment. However, it is important that they must not be expected to react as adults do.

They may feel left out when they miss school or activities with their peers. Giving more detailed explanations that the child can take in and understand would be advisable.

Parents may feel the need to protect their children by limiting them from activities with other children. This is a natural reaction, but it can get in the way of the child’s independence and sense of mastery. Get information from your child’s doctor about what your child can’t do and use that as guidance by supporting the child to take part in school and other activities.

These children do relate to others and reading what other children have to say about their experiences of kidney failure can make them feel less alone. Encourage your child to talk about what he or she feels and thinks. This will teach them how to start to control their emotions and take control of their lives.

Remember that children often show their unhappiness and anxiety by acting out – this is especially true for boys. Changes in behaviour can help to identify a child’s emotional turmoil.

If you as a parent or caregiver feel unable to cope with, or you are unsure as how to deal with your child, it may help to talk to a clinical psychologist, to give further assistance.

My plan to taking charge of my life

Today’s date: ___________________________________________
What’s bothering me? ______________________________________
How does this make me feel? ________________________________
To feel better, I want to be able to... __________________________
I want to do this by... ______________________________________
My plan to taking charge of my life
What I need to do to help me take charge... _____________________
I will ask these people for help... ______________________________

My plan to taking charge of my life

Talk to: _________________________________________________
Find out this information: __________________________________
I will ask these people for help... ______________________________
Adolescents living with chronic kidney disease

As an adolescent there are specific aspects of dealing with the problems of living with chronic kidney disease. We’ve included these in the following information. However, most of what has been talked about in the section for adults would apply to your age group, and should be thought about.

Chronic kidney disease, identity and self-esteem

Your identity and the establishment of self-esteem

Simply put, identity and self-esteem is a sense of self – ‘who am I’. The development of identity and self-esteem is a major, if not the most important, developmental task of adolescence.

The self-concept is a combination of an individual’s physical, emotional, social, intellectual and educational traits. The self-concept is also about who you are as a person. Self-esteem is the value you apply to yourself, such as asking questions like: “Am I special?”, “Am I important?”, “Am I a failure?” As an adolescent you will choose some personal traits that you value and use them to develop self-esteem.

Young people need to pass through psychosocial development during adolescence to have a realistic view of themselves. A task of this developmental process is to achieve a realistic and positive self-esteem.

Show your motivation and determination

Parents and caregivers should be careful not to start to overprotect the adolescent due to the diagnosis of kidney failure, because this will indirectly create a message of “I am unable to look after myself”. This in turn will affect the adolescent’s self-esteem and independence.

Parents have a big effect on an adolescent’s self-esteem. Research has shown that there are three factors linked with good self-esteem in adolescents:

1. Acceptance by parents
2. Clearly defined boundary setting
3. Parental respect for the adolescent and realistic allowance for freedom within the limits of the boundaries.

Chronic conditions may have an effect on your self-esteem

Being chronically ill may make you more likely to be socially isolated and less involved in peer groups. As a result, you may spend more time alone or with your family. It is therefore important to continue with your relationships with your peers because this will help you to develop a positive self-esteem and also allow your peers to learn to accept you.

“Your motivation and willpower will make your friends and family respect you more.”

As an adolescent there are specific aspects of dealing with the problems of living with chronic kidney disease. We’ve included these in the following information. However, most of what has been talked about in the section for adults would apply to your age group, and should be thought about.

Chronic kidney disease, identity and self-esteem

Your identity and the establishment of self-esteem

Simply put, identity and self-esteem is a sense of self – ‘who am I’. The development of identity and self-esteem is a major, if not the most important, developmental task of adolescence.

The self-concept is a combination of an individual’s physical, emotional, social, intellectual and educational traits. The self-concept is also about who you are as a person. Self-esteem is the value you apply to yourself, such as asking questions like: “Am I special?”, “Am I important?”, “Am I a failure?” As an adolescent you will choose some personal traits that you value and use them to develop self-esteem.

Young people need to pass through psychosocial development during adolescence to have a realistic view of themselves. A task of this developmental process is to achieve a realistic and positive self-esteem.

Show your motivation and determination

Parents and caregivers should be careful not to start to overprotect the adolescent due to the diagnosis of kidney failure, because this will indirectly create a message of “I am unable to look after myself”. This in turn will affect the adolescent’s self-esteem and independence.

Parents have a big effect on an adolescent’s self-esteem. Research has shown that there are three factors linked with good self-esteem in adolescents:

1. Acceptance by parents
2. Clearly defined boundary setting
3. Parental respect for the adolescent and realistic allowance for freedom within the limits of the boundaries.

Chronic conditions may have an effect on your self-esteem

Being chronically ill may make you more likely to be socially isolated and less involved in peer groups. As a result, you may spend more time alone or with your family. It is therefore important to continue with your relationships with your peers because this will help you to develop a positive self-esteem and also allow your peers to learn to accept you.

“Your motivation and willpower will make your friends and family respect you more.”

“As an adolescent there are specific aspects of dealing with the problems of living with chronic kidney disease. We’ve included these in the following information. However, most of what has been talked about in the section for adults would apply to your age group, and should be thought about.

Chronic kidney disease, identity and self-esteem

Your identity and the establishment of self-esteem

Simply put, identity and self-esteem is a sense of self – ‘who am I’. The development of identity and self-esteem is a major, if not the most important, developmental task of adolescence.

The self-concept is a combination of an individual’s physical, emotional, social, intellectual and educational traits. The self-concept is also about who you are as a person. Self-esteem is the value you apply to yourself, such as asking questions like: “Am I special?”, “Am I important?”, “Am I a failure?” As an adolescent you will choose some personal traits that you value and use them to develop self-esteem.

Young people need to pass through psychosocial development during adolescence to have a realistic view of themselves. A task of this developmental process is to achieve a realistic and positive self-esteem.

Show your motivation and determination

Parents and caregivers should be careful not to start to overprotect the adolescent due to the diagnosis of kidney failure, because this will indirectly create a message of “I am unable to look after myself”. This in turn will affect the adolescent’s self-esteem and independence.

Parents have a big effect on an adolescent’s self-esteem. Research has shown that there are three factors linked with good self-esteem in adolescents:

1. Acceptance by parents
2. Clearly defined boundary setting
3. Parental respect for the adolescent and realistic allowance for freedom within the limits of the boundaries.

Chronic conditions may have an effect on your self-esteem

Being chronically ill may make you more likely to be socially isolated and less involved in peer groups. As a result, you may spend more time alone or with your family. It is therefore important to continue with your relationships with your peers because this will help you to develop a positive self-esteem and also allow your peers to learn to accept you.

“Your motivation and willpower will make your friends and family respect you more.”
Chronic kidney disease and self-reliance

When you become an adolescent, you need to become more independent. We may call this being self-reliant, acting responsibly, as well as self-management of the disease where possible. Parents need to understand this process. This could mean that as an older adolescent you may want to have some privacy when consulting with your doctor. It might also include looking at and talking about how privacy at home will be respected. For parents of young people with a chronic condition, the difficulty lies in how to keep a management role while helping young people to independently manage their health. Parents may feel blamed for being overprotective when, from their view, they are simply doing their parental duties. The development of self-management methods for adolescents with a chronic condition needs active involvement of both young people and their parents, with attention to the psychosocial world (mental and social world) of the young person. It would be good to begin with self-management because this will help you to stick to your treatment. Self-management will also help you to get to self-reliance as an adolescent with kidney failure.

Chronic kidney disease and your body image

Body image is the changing awareness of one’s body – how it looks, feels, and moves. It is formed by awareness, emotions and physical sensations. It is not static, but can change with your mood, physical experience and environment. As adolescents go through puberty, they experience important physical changes in their bodies. This means they are likely to experience big changes in body image. Body image is influenced strongly by self-esteem and self-evaluation.

An illness can influence the way you view your body

Losing weight or looking ill may create the idea that you are not attractive anymore or that friends do not want to be associated with you. This may become worse when people make negative comments about your body state. Remember that more people will be helpful towards you than the minority of peers that may make nasty comments. The reality however is that when you become ill, changes do happen. You can help work against the negativity by focusing on all your other positive traits.

Speak to your doctor about what to expect and how long body changes may last

If you need a transplant it is okay to ask questions about scarring and how to deal with it. A small scar that will fade is a small price to pay for one’s health! A future boyfriend or girlfriend is not going to fall in love with a scar but with you. Young people are naturally more sensitive about their body image, but as you mature you will become more comfortable with your body. Accept that your physical traits are a given and that you cannot change certain things about your body.

As an adolescent, you still need to work towards building a positive body image for yourself. Body image is how you see your body in your own mind – your own internal view of how you look rather than your actual appearance. Therefore although your condition may affect your body, you still control what you think!

Chronic kidney disease, peer group and intimate relationships

As an adolescent you begin to develop peer relationships more independently. From this peer group of young people the adolescent has to identify and choose someone who will become a significant other. This relationship may develop into an intimate relationship. This is necessary because it allows someone to explore relationships and know who they are attracted to. Having a chronic condition like kidney failure may influence the adolescent’s focus to develop these special relationships. It is however important to encourage these relationships because relationships are important for support and integration into society. It will therefore help with future developments such as work, becoming independent, developing loyalty in relationships and to set structure to one’s life. Relationships with your peer group give you the chance to talk about your emotions and to learn becoming aware of your emotions and how to control them.

“Your condition may affect the way you view your body. Help yourself by focusing on all your other positive traits.”
<table>
<thead>
<tr>
<th>My plan to taking charge of my life</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Today's date:</strong></td>
</tr>
<tr>
<td><strong>What's bothering me?</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>How does this make me feel?</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>To feel better, I want to be able to...</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>I want to do this by...</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>My plan to taking charge of my life</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>What I need to do to help me take charge...</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Talk to:</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Find out this information:</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>I will ask these people for help...</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>