

Addressing the mental health challenges of life with kidney disease

The case for change

Jo Wilton

Contents

	Foreword	3
	Executive summary	4
1	Introduction	8
2	The relationship between kidney disease and psychosocial health	11
3	Living with kidney disease: The impact on people's lives	14
4	Inequalities	19
5	Children and young people	25
6	Kidney-specific psychosocial support	31
7	One size does not fit all	33
8	Person-centred care and coproduction	35
9	Stepped care, screening and assessment	37
10	Working pre-emptively and proactively	41
11	Multidisciplinary working and joined-up care	45
12	The need for psychologically informed kidney care	48
13	Resources	51
14	What have we learned and what needs to happen next?	53
	References	57

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The front cover picture features Sabina Saeed, a kidney transplant patient who participated in our focus groups.

Foreword



Sandra Currie, chief executive, Kidney Research UK

As a former mental health nurse, I know the importance of protecting mental health and the value of good emotional support. Focused care can transform patients' lives and enable them to live as well as possible with the burden of their physical health condition.

Kidney disease takes a huge toll on patients' mental health. Treatments are gruelling, and often fraught with multiple additional complications. In-centre dialysis requires three hospital visits each week lasting at least four hours. A transplant is not a cure, and for many, the fear of rejection hangs over them for the rest of their lives. Research also shows us that patients who are supported with their mental health have better physical health outcomes too.

Kidney patients need access to specialist mental health support – from professionals who understand the unique impact of kidney disease and its treatments, as well as how best to care for the patient's emotional wellbeing. At Kidney Research UK, we are determined to transform the mental health support offered to patients, by funding research to discover the best possible support, and campaigning for access to these essential services for all.

I would like to thank Andy Cole and everyone who has backed the Andy Cole Fund for making this report possible. We will be driving the recommendations forward in order that kidney patients have access to the mental health support they desperately need.



Andy Cole, ambassador, Kidney Research UK

I developed kidney failure after contracting a virus on a trip to Vietnam in 2015. Having played professional football for over 20 years, I found it hard to adjust to living with a life-threatening condition. It took its toll on me – physically and emotionally.

I was very lucky to receive a donated kidney from my nephew. But it's not a cure and getting used to all the medication has been really difficult. I remember getting home after my transplant and looking at all the drugs I had been given and thinking, 'this is what I need to take for the rest of my life to stay alive.'

Living as a transplant patient and not knowing what's around the corner is not easy. But counselling has played a big part in my recovery, and I want everyone with kidney disease to have access to good mental health support like I did.

I'm proud the Andy Cole Fund has supported the development of this report. I want it to shine a light on the impact of kidney disease on people's mental health. It's a really tough disease to live with and patients deserve access to the best possible mental health support.

Executive summary

Purpose

Centre for Mental Health worked with Kidney Research UK to explore the psychosocial (psychological and social) health needs of people living with chronic kidney disease. We reviewed relevant literature and spoke with people living with kidney disease (between the ages of 12 and 88), family members, and professionals in renal (kidney) services, about their experiences. This report shares the key findings from that research and identifies the policy and practice implications for both renal and mental health services.

Key findings

Kidney disease is a risk factor for poor mental wellbeing; and poor mental wellbeing is a risk factor for worse outcomes for people with kidney disease.


Kidney disease can affect people's relationships, their social life, their education, their work, their sense of identity, and their hopes for the future. It is understandable – and even to be expected – that a condition with such wide-reaching effects would also have an impact on people's emotional health, psychological wellbeing and quality of life. These effects can extend to the people who are most closely involved in their care.

"The way I explain it to people is that I just feel like I've got this kidney cloud over my head. It's in my life every day. Every day, it's affecting something that I'm doing."

In general, people living with kidney disease are recognised to be at risk of worse psychosocial outcomes than the general population. But the risk is not equally distributed; some groups are at higher risk than others. Moreover, these groups are often less well served by renal services because, for example, they may also be affected by other long-term health conditions, they may not speak English as their first language, and they may face more barriers to accessing care on the terms on which it is made available by mainstream services.


"I don't think we [people from my community] are hard to reach, I just think we haven't been appropriately approached."

Furthermore, children and young people are not just small adults. They have distinct needs, preferences and risk factors, which must be considered in their own right. The transition from paediatric (children's) to adult care is a time when having the right psychosocial support in place is especially important.



"I always felt like kidney disease is stereotyped to the older generation. And sometimes I just feel that it's really emotionally draining to even explain that to my friends [...] so you just kind of hide it and go, 'Yeah I'm fine.'"

There has been little research into the outcomes of specialised vs. generic psychosocial support, and there is limited availability of kidney-specific psychosocial support (it is a 'postcode lottery'). Yet, the people who spoke to us had a strong preference for kidney-specific psychosocial support.



"Having someone you can talk to about your condition [who understands it], that would be life changing [...] You kind of feel like there is someone else in your corner and it's not like another counsellor who is like, 'Oh right, ok what is [kidney disease]? What does it mean?'"

People's needs and preferences are as diverse as their circumstances and their experiences. There is no 'one size fits all' solution for psychosocial support in kidney disease; an individualised approach is needed.



"I guess I just felt lost as a patient among all the specialities involved."

Person-centred care co-created with patients (coproduction) can mitigate some of the negative impact of kidney disease treatment on psychological wellbeing. It can also help to ensure psychosocial care meets the needs of the people it is intended to support.

At its most basic, good psychosocial support involves having a range of options suitable for different levels of need (stepped care), and mechanisms for ensuring that people are matched to the option most suitable for their level of need (screening and assessment).

Pre-emptive and proactive psychosocial support is better for patients and better for services. There are evidence-based interventions and educational programmes available that can help people to maintain and promote their mental wellbeing. It is easier to protect and maintain mental wellbeing than restore it after it has been eroded.

There are gaps in the systems resulting from a lack of communication, coordination and integration within and between teams and specialisms. These gaps have a negative impact on patients' wellbeing.

Psychosocial support, when done well, is not just an add-on to kidney care, but a strand that runs through every part of it.

"I can't recall one session where the medical doctor asked how I'm feeling mentally. It's just, 'Your kidneys aren't good, we are going to tackle your kidneys.' [...] So you're sent off without knowing what to do next."

Psychosocial support will continue to be inadequate until it is recognised as being a core component of good care for kidney patients, and is funded and staffed accordingly.

"I actually think that the awareness of mental health from the medical team, from the multi-disciplinary team, is actually very high. Whether they have the capacity to actually always deal with what they know is going to be an issue."

Summary statements

All people living with kidney disease should have their psychosocial needs assessed using validated methods. This screening should take place at diagnosis, at changes in treatment, as they go through different stages of kidney disease, at times of distress and annually. This assessment should include the psychosocial needs of family members and carers.

All people living with kidney disease should have access to emotional, psychological and practical kidney-specific psychosocial support appropriate to their level of need: effectively providing a 'stepped care' model. This will require investment in additional support where there are currently gaps, and the provision of a range of support offers so that people can choose the options most relevant to them. Reliable information about the support that is available should be easily accessible through a range of trusted channels, for example the NHS website's pages on chronic kidney disease.

Psychosocial support should be available to those experiencing lower levels of distress and need, and should not be dependent on a person meeting the threshold for a clinical diagnosis or qualifying for specialised social care. This will meet people's needs proactively and pre-emptively as a way of preventing the escalation of distress.

All aspects of kidney care should be psychologically-informed, with all renal health care professionals recognising the importance of psychosocial care, and having the skills (through tailored training), the resources (including time), and the managerial support and supervision to be able to engage with the psychosocial needs of people living with kidney disease.

Psychosocial support for children and young people should be tailored to different development stages, and include a psychologically-informed transition from paediatric to adult care.

Groups at higher risk of kidney health care inequities should be identified so that gaps in provision can be filled. Co-design and coproduction, where support is designed and delivered in an equal partnership between professionals and people using services, will be necessary to ensure support offers are relevant, culturally-competent, age-appropriate, and easily accessible.

The quality of psychosocial support offered to people living with chronic kidney disease should be monitored routinely so that local services can assess how well they are meeting people's needs (including by a range of equality characteristics).

Further research into the provision of psychosocial support for people with kidney disease is under way. It is essential that as the evidence base emerges, it is utilised appropriately to inform the ongoing development of services, and that more research follows to ensure that we continue to learn what works and in what circumstances.

Recommendations

- 1.** The NHS must invest in expanded and improved psychosocial support for people with chronic kidney disease (and other long-term conditions).
 - A.** In England, this could be achieved through the next iteration of the NHS Long Term Plan or the Major Conditions Strategy.
 - B.** In Scotland, the forthcoming strategy on Mental Health and Wellbeing should address the specific needs of people with long-term conditions, including chronic kidney disease.
 - C.** In Wales, this could be included in an updated Together for Mental Health strategy, or a service specification on psychosocial support could be developed as part of the Quality Statement for Kidney Disease.
 - D.** The delivery of the Northern Ireland Mental Health Strategy 2021-2031 should include psychosocial services for people with kidney disease, including children and young people.
- 2.** Integrated Care Boards in England and Health Boards in Scotland and Wales should ensure that a stepped care model of psychosocial support is routinely available to everyone of all ages living with chronic kidney disease in their area.
- 3.** Renal treatment service providers should ensure all of their staff are trained, supported and supervised to identify patients' psychosocial needs, to practice in psychologically-informed ways, and to offer low-level support and rapid onward referral where more intensive support is required.
- 4.** Renal services should routinely assess the psychosocial health of their patients and ask regularly about the quality of psychosocial support they are offered.
- 5.** Government should invest more funding into research on kidney disease and mental health to increase our understanding, and aid the ongoing development of services.

Introduction

"It's just really difficult to explain how much it [kidney disease] has affected me emotionally, you know. It's with me all the time, it's always in my heart and it's always in my mind, and I wish there was someone out there who could help me with that."

In January 2022, Kidney Research UK carried out a patient survey. Over 1,000 people living with kidney disease responded: 67% had experienced symptoms of depression; 27% had considered self-harm or suicide; and 36% couldn't fully take care of their physical health because of their mental health problems; yet 68% had been offered no mental health support (Kidney Research UK, 2022).

When asked what matters most to them, children, young people and adults living with kidney disease consistently give high priority to psychosocial outcomes (Carter *et al.*, 2020; González *et al.*, 2020; Hanson *et al.*, 2020; Natale *et al.*, 2019; Tong *et al.*, 2008; Urquhart-Second, 2016). Psychosocial issues can have a significant impact on people's lives, and they are disproportionately likely to affect those who face the greatest inequalities. Research has shown that psychosocial factors are associated with people's day-to-day functioning, their quality of life, their ability to manage their medical conditions, their medical outcomes and, ultimately, their mortality (Di Matteo *et al.*, 2000; Fukhara *et al.*, 2003; Oh *et al.*, 2019; Onishi *et al.*, 2019; Tonelli *et al.*, 2015). As a result, psychosocial support for people with kidney disease is increasingly widely recognised as "an essential constituent of quality care" (Taylor *et al.*, 2016).

However, although national guidelines for renal services stipulate that people with kidney disease should have access to psychosocial support, what this should look like in practice is not well defined (Department of Health, 2004 & 2005; NICE, 2011). With no minimum standards in place and with limited resources, it can be difficult for commissioners to make a case for prioritising psychosocial support. This has resulted in regional variation in what is available to people living with kidney disease. Screening and assessment of psychosocial needs is rare, pre-emptive support is lacking, and, even in areas where psychosocial resources are more plentiful, these are often not well integrated into the pathways for kidney care.

These gaps in provision have moved people to action. People living with kidney disease, their families, friends and health care professionals are working together to highlight the critical importance of good psychosocial care. In 2021, 'living well with kidney disease' was the World Kidney Day theme; and in 2022, the National Psychosocial Working Group, led by Kidney Care UK, launched a national psychosocial manifesto (Kidney Care UK, 2022a). The aim of this report is to build on that work, bringing together evidence from existing studies and findings from Centre for Mental Health's own research.

In addition to a full literature review, between October and December 2022 we held three focus groups: one for children and young people living with kidney disease; one for adults living with kidney disease and unpaid carers; and one for researchers and health professionals. We also conducted a series of one-to-one interviews. In total, we spoke to 11 people living with kidney disease ranging in age from 12-88 years old; six were female, five male; and four identified as being from a racialised

community. We spoke to three unpaid carers. And we spoke to seven people involved in kidney care in a professional capacity, including nephrology, liaison psychiatry, clinical psychology, research, social work and physiotherapy.

The report brings together the voices of the people who participated in the focus groups and interviews, and findings from previous studies. It identifies challenges and opportunities, and gaps in our knowledge. It considers promising developments, areas where there is room for improvement and what we can learn from other long-term conditions. And it concludes with a vision in which psychosocial support becomes an integral part of kidney care, with every person living with kidney disease able to access a form of support appropriate to their needs and their individual circumstances.

The report's scope covers a wide range of emotional and psychosocial health issues. It does not cover dementia or cognitive impairments as separate issues, except where they relate to people's mental health needs.

Definition of terms

Kidney disease

In this report 'kidney disease' will be used as shorthand for 'chronic kidney disease'. Chronic kidney disease refers to any abnormality of the kidneys that lasts more than three months. There are various stages of kidney disease, ranging from mild loss of kidney function to complete kidney failure.

Psychosocial care

"Psychosocial care is recognised as a key element of person-centred care. It captures the importance of considering the broad range of determinants affecting emotional well-being (including biological, psychological, social and environmental factors) and that there are a range of beneficial interventions that are delivered by a variety of professionals including Clinical, Health and Counselling Psychologists, Social Workers, Counsellors and Psychiatrists." (Kidney Care UK, 2022a)

Psychological care

Mental health support, usually in the form of talking therapies, with the aim of improving a person's psychological wellbeing. This will often be delivered by psychotherapists, psychologists or other mental health clinicians.

Severe mental illness

Mental health problems including schizophrenia and bipolar, often causing severe impairment to daily life and functioning.

Kidney replacement therapy

Therapy which replaces the normal blood-filtering function of the kidneys. It includes dialysis and transplantation.

Uraemia

Abnormally high levels of waste products in the blood due to kidney failure.

A note on terminology regarding race and ethnicity

We are aware that the terminology used to discuss race and ethnicity in policy and research contexts is sometimes highly problematic. For this reason, wherever possible we have used the term 'racialised communities'. This is because ethnic, racial and cultural communities who are in the minority have been racialised – that is, white-majority systems have categorised groups according to the colour of their skin or other cultural or religious features, and in doing so have 'othered' and marginalised them. Exceptions to our terminology are made when quoting other organisations' research. Learn more in our [terminology guide](#).

The relationship between kidney disease and psychosocial health

The relationship between kidney disease and psychosocial health is complex. The National Psychosocial Working Group (2022a) has outlined three forms it can take:

1. Kidney disease can impact a person's mental health
2. Pre-existing trauma or mental illness can lead indirectly to kidney failure
3. Co-existing mental illness, dementia or intellectual disabilities with kidney disease leads to poorer outcomes.

The association between poor mental health and kidney disease is supported by a large body of evidence. The mechanisms underpinning this relationship are not well understood and need further research (Simoes e Silva *et al.*, 2019; Tian *et al.*, 2021). However, what is clear is that they are complex: there are biological, psychological and social factors at play; and there are inter-relationships and feedback effects between these factors.

Depression

The evidence for a relationship between kidney disease and depression is robust and long-standing. People living with kidney disease are significantly more likely to experience depression than the general population (Alshelleh *et al.*, 2022; Hedayati *et al.*, 2009; Ma *et al.*, 2016; Palmer *et al.*, 2013; Tian *et al.*, 2021). The prevalence varies according to what stage of kidney disease someone is in, what treatment they are receiving, their perception of their illness and a range of psychosocial factors (Clarke *et al.*, 2016; Palmer *et al.*, 2013). Depression in kidney disease is associated with poorer quality of life, increased symptom burden, reduced treatment adherence, faster disease progression and increased mortality (Chiang *et al.*, 2015; Farrokhi *et al.*, 2014; Katon, 2022; Palmer *et al.*, 2013; Seng *et al.*, 2020; Shirazian *et al.*, 2017; Tsai *et al.*, 2012). There is also limited evidence that depressive symptoms are associated with a decline in kidney function in adults who do not have kidney disease (Zhang *et al.*, 2021).

Assessment of depression in people with kidney disease is complicated by some overlap between the symptoms of uraemia and depression (Cukor *et al.*, 2006; Shirazian *et al.*, 2017). Nevertheless, there are screening tools with evidence of reliability for use with people living with kidney disease (Dano *et al.*, 2022; Kondo *et al.*, 2020; Tian *et al.*, 2021; Watnick *et al.*, 2005). The gold standard is assessment by clinical interview (Kimmel, 2002; Tian *et al.*, 2021).

Anxiety

Anxiety is also more prevalent among people living with kidney disease than the general population (Alshelleh *et al.*, 2022; Schick-Makaroff *et al.*, 2021), and has received less research attention than depression. However, there is evidence that it is associated with poorer quality of life, non-adherence to medical treatment and worse health outcomes (Alosaimi *et al.*, 2016; Donahue *et al.*, 2021; Huang *et al.*, 2021; Schouten *et al.*, 2019). A recent systematic review and meta-analysis identified the following risk factors for higher levels of anxiety among people with kidney disease: depression, lower parathyroid hormone levels, having other health conditions, longer stays in hospital, lower perceived quality of life, and lower vitality levels (Huang *et al.*, 2021).

Psychological trauma

People who have experienced adversity in childhood are at higher risk of a range of long-term mental and physical health conditions (Hughes *et al.*, 2017). Whether adverse childhood experiences (ACEs) are associated with a higher risk of kidney disease in particular needs further study (Clark, 2021).

Research indicates that those who have kidney disease and a history of ACEs may be at higher risk of mortality (Ozieh *et al.*, 2020). There is also evidence of an association between stress-related disorders, including post-traumatic stress disorder (PTSD), and faster progression of kidney disease (Koraishy *et al.*, 2023; Su *et al.* 2021).

People who are living with kidney disease may also be at higher risk of psychological trauma. There is evidence that experiences relating to the treatment of critical illnesses can lead to PTSD (Parker *et al.*, 2015). To date, much of the research has focused on people who have been admitted to an intensive care unit (Hatch *et al.*, 2018). Many people living with kidney disease find treatments intrusive and distressing, and there is some evidence from people who have received kidney transplants that they are at higher risk of PTSD (Nash *et al.*, 2022). There has also been speculation that, for people who receive in-centre dialysis, witnessing distressing medical events or the unexplained absence of other people receiving dialysis may be risk factors for PTSD (Ramer *et al.*, 2021). However, further research is needed to establish the accuracy of this finding and to investigate whether people who receive other forms of kidney replacement therapy are also at higher risk of psychological trauma.

Severe mental illness

Kidney disease is more prevalent among people living with a diagnosis of severe mental illness (Iwagami *et al.*, 2022). The factors underpinning this relationship are complex. Some of the association is accounted for by the fact that people with severe mental illness are at higher risk of conditions such as diabetes and hypertension which, in turn, are risk factors for kidney disease; some is due to the long-term use of lithium, prescribed for various mood disorders which can damage the kidneys; and other factors are likely to be involved (Bitan *et al.*, 2019; Cogley *et al.*, 2022; Iwagami *et al.*, 2022). People living with severe mental illness also experience worse medical outcomes in kidney disease and face other health inequalities, which are discussed in more detail below.

Psychological medication

The evidence of the effects of antidepressants causing kidney disease is limited and the data are inconclusive (Chopra *et al.*, 2021; Gregg & Hedayati, 2020; Hedayati *et al.*, 2017; Palmer *et al.*, 2016; Pearce *et al.*, 2022). Lithium, often prescribed as a mood stabiliser, is a known risk factor for kidney disease, especially among older adults and those who have long-term prescriptions (Golic *et al.*, 2022; Højlund *et al.*, 2022; Pahwa *et al.*, 2021; Schoretsantis *et al.*, 2022; van Alphen *et al.*, 2021). Some studies have also observed an increased risk from other psychotropic medications (provided for people with psychosis) but the evidence is less robust (Damba *et al.*, 2022; Carswell *et al.*, in press).

Covid-19

People living with kidney disease were classed as a vulnerable group during the pandemic, especially those whose immune systems were suppressed. While the pandemic created poorer mental health among the population as a whole, there were particular challenges for people with long-term health conditions.

Older adults with kidney disease experienced a more negative impact on their psychological wellbeing as a result of Covid-19, including increased depression, increased anxiety and lower quality of life (Voorend *et al.*, 2021).

For those whose immune systems do not respond adequately to the Covid-19 vaccine, the pandemic is an ongoing source of anxiety. Surveys demonstrate that significant levels of distress remain among the immunocompromised population (Pearce *et al.*, 2023).

Key points

The relationship between kidney disease and mental wellbeing is well-established. Kidney disease is a risk factor for poor mental wellbeing; and poor mental wellbeing is a risk factor for worse kidney disease outcomes.

Living with kidney disease: The impact on people's lives

As people with kidney disease are frequently reminded, there is no cure for their condition; it is something they will live with for the rest of their lives. The burden of treatment for kidney disease is among the highest of all long-term conditions, and the symptom burden is also high. Research has identified various stressors associated with kidney disease. These include living with dietary restrictions, changes to family dynamics, functional limitations, financial difficulties, and the awareness of their mortality risk (Cukor *et al.*, 2007).

Consequently, kidney disease can have a significant impact on people's work, social lives, relationships, education, sense of self and their hopes for the future (McKie *et al.*, 2022a). It is understandable – and even to be expected – that a condition with such wide-reaching effects will impact people's emotional health, psychological wellbeing and quality of life. As one person said in one of our focus groups:

"The way I explain it to people is that I just feel like I've got this kidney cloud over my head. It's in my life every day. Every day, it's affecting something that I'm doing."

Adjusting to life with kidney disease

Adjusting to life with kidney disease is not a one-off event. For many people, it is an ongoing process, which sometimes fades into the background, only to return to the foreground at important transitions (De Jong *et al.*, 2021). These transitions are often connected to stages of illness or treatment, for example, receiving a diagnosis, entering end-stage kidney disease, starting dialysis, or receiving a transplant; and to new life phases, such as leaving home or starting a family.

In our focus groups and interviews, the feelings that came up most often were worry, uncertainty, grief, frustration and isolation.

"There's a lack of [recognition of] the grief reaction to finding out you've got this significant, life-changing diagnosis – and I would say 100% of people are going to go through that in one way or another, and I don't think that's normalised enough."

One young person described living with kidney disease as "like you're playing roulette with your life and not actually knowing what the outcome is going to be because none of the specialists can tell you." Some people spoke about the difficulties of being perceived as an object of pity:

"I feel like sometimes people look at you and think, 'What a shame, you've had two transplants.'"

"People don't perhaps think I'm capable of aspiring to better things because I'm not well."

Other people spoke about becoming more socially isolated as a result of living with kidney disease:

"Another thing that's been really hard on me is the impact on my social life. People don't understand how hard it is to miss out on things."

"I've learnt to almost enjoy my own company because when I'm not well, I'm home a lot. For me, I feel like it's easier to stay in my own company. I don't have to entertain people or [...] worry whether I'm going to be ill, or explain that circumstance for anybody just because of all that add-on stress of not knowing how people are going to react [...]. So, in recent years, I don't go out as much as I used to do just because I find it a lot easier."

The symptom burden

People living with kidney disease experience a range of symptoms associated with their condition. The combined severity and impact of these symptoms is often referred to as the symptom burden. The symptom burden is one of the strongest predictors of reduced quality of life among people living with kidney disease, and it can also have a significant impact on people's ability to perform day-to-day activities and to manage their own health (Brown *et al.*, 2018; Magadi *et al.*, 2022; van der Willik *et al.*, 2021; Yapa *et al.*, 2021).

Symptoms vary across the stages of kidney disease and across the different types of treatment (Fletcher *et al.*, 2022). Overall, those most commonly reported are fatigue or lack of energy, drowsiness, pain, itchiness and dry skin (Almutary *et al.*, 2013; Clark-Cutaia *et al.*, 2022). There is evidence that these symptoms often occur in clusters (Lockwood *et al.*, 2018; Moore *et al.*, 2022; Pugh-Clarke *et al.*, 2017). They may also occur alongside, or be amplified by, symptoms of other health conditions (Almutary *et al.*, 2013; Barsky & Silbersweig, 2022). This last point is worthy of note, as a significant proportion of people with kidney disease are living with at least one other long-term health condition (Hawthorne *et al.*, 2023; MacRae *et al.*, 2021).

A study conducted in the US asked 119 people receiving haemodialysis which of their symptoms were their highest priority for treatment (Flythe *et al.*, 2018). They prioritised physical symptoms of insomnia, fatigue and muscle cramps and the mood symptoms of anxiety, depression and frustration. Many of these symptoms are both unpleasant in their own right and compromise people's ability to do the activities they enjoy. For example, a review of 65 studies of fatigue in haemodialysis identified four themes:

1. Debilitating and exhausting burden of dialysis
2. Restricted life participation
3. Diminishing capacities to fulfil relationship roles
4. Vulnerability to misunderstanding (because fatigue is often invisible to other people)

(Jacobson *et al.*, 2019)

These themes encompass physical and emotional feelings, questions of social identity and independence, and the need to find meaning and joy in life. Psychological, social and physical aspects of the symptom burden cannot be neatly separated out; they are closely connected to one another.

And symptom burden can make it more difficult for people to do things that are known to be good for psychological wellbeing (e.g. nausea, tiredness and shortness of breath can make it uncomfortable to be physically active).

The treatment burden

'Treatment burden' refers to the work a person must do to manage their health conditions, and the impact this has on their wellbeing and functioning (Eton *et al.*, 2012). It includes activities such as taking and managing multiple medications, arranging and attending health care appointments, following advice relating to diet and exercise, and monitoring health (Eton *et al.*, 2013; Fraser & Taal, 2020). In-centre haemodialysis has one of the heaviest of all treatment burdens, owing to its inflexible treatment schedules (Sousa *et al.*, 2023). A heavy treatment burden is associated with more difficulties coping with kidney disease and lower health-related quality of life (Hounkpatin *et al.*, 2020; Tesfaye *et al.*, 2020).

Treatment burden is shaped by life circumstances and it intersects with health inequalities. For example, two people may be undergoing the same treatment but one person may experience a greater burden because they are having to fit their treatment around work commitments and childcare responsibilities; another person may experience a greater burden because they are more unwell and have less energy to spare for managing and attending appointments; and another may experience a greater burden because they have entered treatment suddenly and without preparation (often referred to as 'crashlanding') (Hounkpatin *et al.*, 2020). Analysis by the Health Foundation (2020) of data relating to long-term conditions has shown that the treatment burden can be greater for people who are living with more than one condition, especially if they are living in more deprived circumstances. As one person said in one of our interviews, "People aren't just dealing with kidney disease, they're dealing with other life issues."

A person's treatment burden is the sum of different sorts of costs. There may be a literal price to pay when, for example, paying for a prescription, parking at the hospital or reducing hours of employment. There may be costs in terms of time and energy when, for example, travelling to clinics and receiving treatment. And, relevant to this report, there may be an emotional toll associated with the experience of treatment, and interactions with health care professionals and the health care system. O'Hare and colleagues (2018) asked 27 people living with kidney disease about their experiences with illness, and about interactions with health care professionals and the health system. Their questions did not probe for emotions, nevertheless people described feelings of isolation, abandonment, alienation, mistrust and self-blame.

The impact on unpaid carers

“My kidney issues, they’ve affected my family a lot. A lot. More than me, probably.”

There is a wealth of research demonstrating the positive impact of social support on psychosocial outcomes in kidney disease (Cohen *et al.*, 2007; Fuertes *et al.*, 2021; Patel *et al.*, 2005; Tommel *et al.*, 2021; Untas *et al.*, 2011). For many people who are living with kidney disease – especially children, young people and older adults – families, partners, and friends play a vital role as unpaid carers (Gayomali *et al.*, 2008; Sharma *et al.*, 2019). Sometimes this support is in addition to the psychosocial care provided by the renal unit; sometimes it is making up for shortfalls in the psychosocial support available through the health care system.


Many of the people living with kidney disease who spoke to us said their families are their main sources of support, but some hesitate to ask for as much help as they need because they worry about being a burden. The families who spoke to us were clear they wanted to do everything they could to support their loved ones. However, they were concerned that there were forms of support that only professionals could provide. As one parent said:

“They [the people living with kidney disease] need both, don’t they? They need the family support, but they need professional support as well, it’s not either/or.”

“And of course you have your loved ones around you but, for me, I’m very much conscious of the burden that I place on them.”

Being a carer for someone living with kidney disease takes an emotional toll, and this holds true across different forms of kidney replacement therapy and conservative care (where a patient chooses not to go on dialysis or have a transplant, often because they are too frail) (Bardak *et al.*, 2019; Sajadi *et al.*, 2017; Seephom *et al.*, 2021; Shukri *et al.*, 2020; Walavalker *et al.*, 2022). Several studies have found a relationship between the psychological wellbeing of people living with kidney disease and their unpaid carers (Fu *et al.*, 2022; Pereira *et al.*, 2017; Sajadi *et al.*, 2017; Vovlianou *et al.*, 2023).

The importance of caring for the carers, both as a means of improving outcomes for people with kidney disease and an essential aim in its own right, is widely recognised in the literature (Hoang *et al.*, 2018; Kim & Lee, 2022; Matthews *et al.*, 2021; Vovlianou *et al.*, 2023). Pereira and colleagues (2017) recommend: “[I]nterventions that consider both groups together and individually must be implemented.” Similarly, Sousa and colleagues (2023) have advocated “promot[ing] the perception of chronic disease as a ‘we’ challenge rather than an individual problem” and, in the same paper, they outline what good support, which responds both to the needs of people living with kidney disease and those of their unpaid carers, could look like.



"I think, for the people involved in your life, the lack of counselling for them as well is also not a good thing at all."

It is also important, however, not to see caregiving as solely a burden or a negative experience; and to note that people may bring or gain strength through this process. As Hoang *et al.* (2018) observed:

"The unique finding in this review is the positive impact caregiving experience has among those providing the care. It was apparent that the caregivers' emerging confidence and strength contributed to their ability to cope with the burden of caregiving. [...] The informal caregivers' development of resilient abilities during their caregiving experiences is an important factor that strengthens and sustains the caregiving relationship."

Key points

Kidney disease can affect people's relationships, their social life, their education, their work, their sense of identity, their hopes for the future, etc. It is understandable – and even to be expected – that a condition with such wide-reaching effects would also have an impact on people's emotional health, psychological wellbeing and quality of life. These effects can extend to the people who are most closely involved in their care.

Inequalities

Not everyone in the UK is equally likely to be affected by kidney disease; and, of those who are affected, some have more risk factors than others for poor psychosocial outcomes.

Groups at higher risk of kidney disease include:

- People from Black and South Asian backgrounds
- People experiencing financial hardship
- Older adults
- People with a lower level of education
- People living with severe mental illness
- People living with type 2 diabetes
- People living with hypertension.

(Crews and Novick, 2019; Grant *et al.*, 2023; Kidney Research UK, 2018; Kovesdy, 2022; Li *et al.*, 2022; Park *et al.*, 2021; Thio *et al.*, 2020; Zeng *et al.*, 2018)

There have been few studies looking at the risk of poor psychosocial outcomes among people with kidney disease and, accordingly, these findings are less robust. However, the available evidence indicates that the following groups are at increased risk:

- People receiving haemodialysis, compared with other forms of kidney replacement therapy
- People who start dialysis suddenly and without preparation
- People experiencing social deprivation
- People who do not have a partner
- Younger people
- Older adults
- Women
- People from racialised communities
- People living with severe mental illness
- People living with multiple long-term physical health conditions
- People with lower levels of educational attainment.

(Carswell *et al.*, in press; Damery *et al.*, 2019; Driollet *et al.*, 2019; Kefale *et al.*, 2019; Krishnan *et al.*, 2020; Mendelssohn *et al.*, 2009; Ng *et al.*, 2021; Park *et al.*, 2015; Tao *et al.*, 2019)

This section will briefly outline the ways in which risk factors cluster together meaning that certain groups of people are disproportionately likely to experience poorer mental health outcomes.

People from racialised communities

Although kidney disease has been described as “an important clinical condition beset with racial and ethnic disparities that are associated with social inequities” (Eneanya *et al.*, 2021), a combination of genetic, biological and social factors lead to a higher prevalence of kidney disease in people from certain communities.

Until recently, due to research that overestimated kidney function in Black people, guidelines recommended that doctors should adjust readings using a proposed correction factor for ethnicity when testing for kidney function in Black people. This recommendation has now been removed from NICE guidelines.

Eneanya and colleagues (2021) have argued that what Black people share is not a biological identity – there is great diversity within Black communities – but a high risk of being harmed and disadvantaged by racism. Mohottige and colleagues (2022) elaborate on this point in their discussion on the use of ‘race’ in kidney research and medicine. They write:

“The use of race in research and medicine is complex yet necessary. Race should be recognized in medicine—not because it is a fixed trait approximating a biologic characteristic but because it is a latent group concept that helps to capture group-level health outcomes that are linked to racism, which selectively and differentially exerts its effects on individuals’ health on the basis of their racially stratified social status. Responsible, equity-focused, and race-conscious approaches are required to disrupt long-standing and harmful conventions.”

However, it must be recognised that there are several important biological and genetic factors which may impact the prevalence of kidney disease in certain groups, and explain why disease in some populations progresses faster resulting in kidney failure sooner. These include hypertension, diabetes (more prevalent in Asian and South American populations) and genetic predisposition (for example, focal segmental glomerulosclerosis – a family of diseases which damage the kidney – is especially seen in Black African populations, and other disorders such as lupus occur predominantly in African and Caribbean populations).

Researchers and clinicians must hold the concept of race in mind, not only because there are well defined biological differences and genetic susceptibilities, but also there is a degree of social construct that can feed into a person’s likelihood of experiencing discrimination, deprivation and marginalisation and how likely they are to seek medical advice and use the health services available.


One of the consequences of racism in the UK is health inequity. People from racialised communities are more likely to experience discrimination and prejudice; they are at greater risk of financial hardship and food insecurity; they are less likely to have access to appropriate accommodation; and they face greater barriers to employment (HM Govt, 2021; Loopstra, 2020; TUC, 2022). These factors may lead to chronic stress, trauma and increased exposure to harmful environments which, in turn, result in a higher risk of a range of long-term conditions, poorer medical outcomes and poorer psychosocial outcomes (Arriola *et al.*, 2021; Damery *et al.*, 2019; Hayanga *et al.*, 2023; Lunyera *et al.*, 2020; Mathur *et al.*, 2018; Norton *et al.*, 2016).

Health inequities not only affect people’s risk of developing health conditions, they also affect the treatment they receive. People from South Asian and Black backgrounds in the UK are significantly more likely to need kidney replacement therapy than people from white backgrounds, but significantly less likely to receive a transplant (Kidney Research UK, 2018; UK Renal Registry, 2022) or to be receiving home therapies, despite NICE guidelines supporting them (National Kidney Federation,

2023). The inequity in access to transplants is especially concerning in the context of this report, given that transplants are associated with better psychosocial outcomes (Fletcher *et al.*, 2022; Purnell *et al.*, 2013; Tonelli *et al.*, 2011).

However, there are also challenges in encouraging donors from racialised communities to facilitate transplantation in this population. This is in part, perhaps, related to the need for more education and advice.

Historically, people from racialised communities have often been labelled by public services as 'hard to reach'. However, as a participant in our interviews said,



"I don't think we [people from my community] are hard to reach, I just think we haven't been appropriately approached."

'Reaching' someone is a form of connection; it is a relational concept. The strength of the therapeutic alliance – the relationship between health care professionals and patients – is associated with improved quality of life and adherence to treatment and, as such, is a crucial aspect of psychosocial care (Blumrosen *et al.*, 2020; Fuertes *et al.*, 2017; Toporovsky *et al.*, 2022). The act of 'reaching' and establishing trust is ultimately the job of the professionals, not the patients in these circumstances.

Similar inequities are experienced by other groups of people who face marginalisation and discrimination, but who get labelled as 'hard to reach' by services: including those with long-term mental health problems.

The importance of strengthening the clinical relationship between health care professionals and people from racialised communities has been discussed in a range of studies. For example, Sharma and colleagues (2019) researched the ways in which people from South Asian backgrounds experience life on haemodialysis in the UK. One of their findings related to negative experiences of interactions with clinicians. The authors note that, while this finding is not unique to people from South Asian backgrounds, it may be exacerbated by factors such as language and conceptual barriers, and clinicians failing to build a rapport with the broader family network, which mean that signs of depression are missed and opportunities to offer help are not taken (Thomas, 2023). More broadly, there is evidence that Black people report poorer doctor-patient relationships than white people (Shen *et al.*, 2018).

To address this disparity, one approach is to utilise interventions that improve the cultural competence of health care professionals (Handtke *et al.*, 2019). Another is to offer a different relational dynamic through the use of peer navigators and peer educators (Corrigan *et al.*, 2014; Natale-Pereira *et al.*, 2011; see also, Box 1). The answer is unlikely to be either/or, but both-and, with the 'and' referring to forms of support that are only likely to be identified when research and health care learn to truly listen and respond to the needs and preferences of people from racialised communities. Mohottige and colleagues (2021a) have outlined ways in which anti-racist principles can be applied to kidney care, with the goal of achieving health equity.

Another solution is the immense work ongoing in increasing access to medicine as a career to less privileged communities with widening gateway programmes to medical schools in the UK.

Box 1: Kidney Research UK, Peer Educator Initiative

“Kidney Research UK has been running highly successful multi-award winning and evidence based peer educator projects with people from underrepresented and minority ethnic groups across the UK for over 17 years. Recruited and trained by the charity, peer educators are people who work closely with, and provide emotional support to, individuals, families, community groups and faith groups in their own communities. They undertake a bespoke, accredited, training course, and are equipped to deliver specific health messages.

They offer practical help and advice, and psychological support, in the context of their own language and culture, explaining potential reasons for increased risk and suggesting lifestyle changes that could help to prevent disease. They often have lived experience of treatments available for people with kidney failure.

Peer educators have offered advice and support to many thousands of people from minority ethnic and underrepresented groups and have encouraged thousands of people from these groups to join the NHS organ donor register.”

(Kidney Research UK, 2023)

People with severe mental illness

People living with a diagnosis of severe mental illness die 10 to 20 years earlier than the general population (Liu *et al.*, 2017; de Mooij *et al.*, 2019; Walker *et al.*, 2015). Much of this mortality gap results from poor physical health (Firth *et al.*, 2019). Kidney disease is more prevalent among people with severe mental illness (Bitan *et al.*, 2019; Iwagami *et al.*, 2022). Some of the increased prevalence is accounted for by lithium treatment and higher rates of cardiovascular disease (Cogley *et al.*, 2022; Iwagami *et al.*, 2022). In addition, people who are living with both kidney disease and severe mental illness have higher mortality rates and higher rates of hospitalisation than people who are living with kidney disease but not with severe mental illness (Cogley *et al.*, 2022; Tonelli *et al.*, 2015).

People with severe mental illness face difficulties accessing treatment for physical health problems (Foye *et al.*, 2020). These difficulties can include the type of treatment they are, or are not, offered. For example, kidney patients with severe mental illness are less likely to receive a kidney transplant than those without severe mental illness, despite lack of evidence of worse transplant outcomes (Bitan *et al.*, 2019; Butler *et al.*, 2017; Carswell *et al.*, in press; Iwagami *et al.*, 2022; Molnar *et al.*, 2018).

The difficulties faced by people with severe mental illness also include the way in which treatments are offered. For example, renal units have been described as “task-orientated environments” and renal nurses – who are the first point of call for most difficulties – may lack resources, in terms of time, training and managerial support, to provide holistic care to people with severe mental illness (Alexander *et al.*, 2016; Alwar & Addis, 2022; Foye *et al.*, 2020). In this context, patients who are unable to easily fit into the busy ward routine are at risk of being labelled disruptive or non-compliant (Janosevic *et al.*, 2019).

People living with severe mental illness also face additional barriers to managing their physical health conditions. As Carswell and colleagues (2022) have noted, physical health can be of secondary importance to distressing and debilitating mental health symptoms. Some barriers to caring for people with severe mental illness that have been identified by renal nurses include the vigilance of the units they work in, staff shortages, and a lack of training in mental health (Alwar & Addis, 2022).

There is limited evidence for how to improve kidney care – or long-term condition care, more generally – for people living with severe mental illness. However, recommendations that have been made include: educating renal staff about the needs of people with severe mental illness; renal teams working more closely with psychiatry teams; and greater support from managers in taking additional time to support people with severe mental illness (Cogley *et al.*, 2022; Lafontaine *et al.*, 2022; Sharrock *et al.*, 2022).

Older adults

Although the experience of ageing varies from person to person, the term ‘older adult’ typically refers to people aged 65 years or older (NHSE). According to the UK Renal Registry 24th Annual Report, 37% of people in the UK receiving kidney replacement therapy in 2020 were older adults (UK Renal Registry, 2022).

Older adults, when compared with other people living with kidney disease, are more likely to experience a number of risk factors for poor psychosocial outcomes. They are also more likely to be living with more than one long-term condition (Bowling *et al.*, 2017; Liu *et al.*, 2023). Each additional long-term condition brings a greater symptom burden and treatment burden, and increases the likelihood of harmful interactions between different medications (Hounkpatin *et al.*, 2020; Mohottige *et al.*, 2021b; Wastesson *et al.*, 2018). They are more likely to be living with a neurodegenerative condition, such as Alzheimer’s (Yaffe *et al.*, 2010). They are more likely to experience frailty, which is associated with depression and lower health-related quality of life in people living with kidney disease (Chi *et al.*, 2022; Nixon *et al.*, 2020). They are more likely to be socially isolated (Nicholson, 2012). And, as with people from racialised communities and people living with severe mental illness, they are less likely to receive a kidney transplant, despite this form of treatment being associated with better psychosocial outcomes (Kidney Research UK, 2018; Melandro *et al.*, 2021).

These risk factors for poor psychosocial wellbeing are crucial to address in older adults. Research indicates that psychological wellbeing and health are more closely linked at older ages in the general population (Steptoe *et al.*, 2015). For people in later life across the whole population, mental health has a greater impact on life satisfaction than physical health (Puvill *et al.*, 2016). In a survey of 271 older adults in the United States, the psychosocial outcome of maintaining independence was the highest priority (49%), ahead of staying alive (35%) and reducing pain (9%) (Ramer *et al.*, 2018). Schoot and colleagues (2022) also found that health priorities for older adults were mostly related to quality of life.

However, older adults face barriers to accessing some forms of psychosocial support. Some of these barriers relate to physical limitations to mobility, including frailty, reduced access to means of transport, and isolation. Others relate to the ‘digital divide.’ Older adults are less likely to have access to digital technologies; they are less likely to have skills for using digital technologies; and they are more likely to need adaptations to accommodate difficulties with sight, hearing, mobility and cognitive impairments (Frydman *et al.*, 2022; Lopez de Coca *et al.*, 2022; Mao *et al.*, 2022; Moody *et al.*, 2022; Morrison *et al.*, 2023). As more psychosocial support moves online, there is a risk that this could widen inequalities, unless efforts are made to address these challenges. Initial research into age-friendly digital health care has been carried out, but the recommendations are in need of refinement and testing (Moody *et al.*, 2022; Wardlow *et al.*, 2022).

Bowling and colleagues (2017) identified complexity as the central theme in their interview study of 30 older adults living with kidney disease in the United States:

“Older adults with CKD [chronic kidney disease] must negotiate the complexity that arises when they are asked to adhere to discordant treatment recommendations. They experience this in the context of differing personal abilities to cope with complexity and within a health care environment that is not organized to address multiple chronic conditions.”

Fried and colleagues (2011) note that a disease-specific approach to care may be especially inappropriate for older adults with multiple chronic conditions and, instead, they recommend moving to an approach directed by the person's individual priorities. This means, for example, that shared decision-making for older adults needs to focus on their overall goals, not just those relating to a single medical condition (Schoot *et al.*, 2022).

Key points

As a whole, the population of people living with kidney disease are at risk of worse psychosocial outcomes than the general population. But the risk is not equally distributed; some groups are at higher risk than others. Moreover, these groups are often less well served by renal services because, for example, they may be affected by other long-term health conditions, they may not speak English as a first language, and they may face more barriers to accessing care on the terms on which it is made available by mainstream services.

Children and young people

Kidney disease has a significant negative impact on the quality of life and mental health of children and young people (Francis *et al.*, 2019; Hamilton *et al.*, 2019; Splinter *et al.*, 2018; Tjaden *et al.*, 2016; van Muilekom *et al.*, 2021). This impact is seen across their emotional, social, physical and educational wellbeing and functioning (Kerklaan *et al.*, 2020; Ruidiaz-Gómez & Higuaita-Gutiérrez, 2021; Rupp *et al.*, 2021). And, as in adults, there is evidence that psychosocial issues have a negative impact on the medical outcomes of children and young people (Clementi & Zimmerman, 2020; Hamilton *et al.*, 2018).

In a multinational interview study of 30 young adults (aged 18-36) living with kidney disease, Kerklaan and colleagues (2020) identified six themes relating to their psychosocial wellbeing:

1. Struggling with daily restrictions (debilitating symptoms and side effects, giving up valued activities, impossible to attend school and work, trapped in a medicalised life, overprotected by supporting adults and cautious to avoid health risks)
2. Lagging and falling behind (delayed independence, failing to keep up with peers and struggling socially)
3. Defeated and hopeless (incapacitated by worry, an uncertain and bleak future, feeling unworthy of relationships, low self-esteem and shame)
4. Reorienting plans and goals (focusing on the day-to-day, planning parenthood and forward and flexible planning)
5. Immersing themselves in normal activities (refusing to miss out, finding enjoyment, determined to do what peers do and being present at social events)
6. Striving to reach potential and seizing opportunities (encouragement from others, motivated by the illness, establishing new career goals and grateful for opportunities).

While some of these themes hold true for adults living with kidney disease, others are more distinctly tied to the challenges and opportunities of young adulthood. It is important that the needs and preferences of younger people living with kidney disease are considered in their own right, to ensure they receive support appropriate to their stage of life.

As Kula and colleagues (2021) emphasise, “Children with CKD [chronic kidney disease] are not little adults with CKD”; there are compelling reasons why they warrant special attention.

Changes and transitions

Childhood, adolescence and young adulthood are life-stages full of changes. The needs of a two year old are very different from those of a ten year old which, in turn, are very different from those of a twenty year old. One of the most significant changes over these life-stages is from complete dependence on families and caregivers at the start of life to, for most young people, relative independence by their early twenties. This development is gradual and does not happen at the same pace for all.

In contrast, for some of the young people and parents who spoke to us, the transition from paediatric to adult care was relatively abrupt and took place at a 'cut-off' age. About 35% of young adults lose a successfully functioning kidney transplant within 36 months of moving from paediatric to adult care (Harden *et al.*, 2012), making this an especially high-risk time in their life.

One young person described how quickly and with how little preparation the change took place:

"There was literally a handover in ten minutes, there wasn't any like gradually going in, or any discussion between the two hospitals [paediatric and adult]. So, they kind of just hand over my history, and I had to basically explain all my background again to the new doctors because all they had was blood results and tests, nothing really about how I have been with it [...] There was no 'Are ok with it?' or 'Are you ready for this?'"

Another young person said:

"It would be nice to be introduced to the new doctors beforehand. Yeah, there was not much to it, there was not much thought behind it."

And a mother, talking about her daughter's transition from paediatric to adult care, described it as "being thrown in at the deep end."

This transition is a vulnerable stage for young people, when their condition and their psychosocial wellbeing may deteriorate (Dallimore *et al.*, 2018). Young adults have worse outcomes following a kidney transplant than any other age group (Hamilton *et al.*, 2020; Pankhurst *et al.*, 2020). This is likely to have an impact on overall life-expectancy, as well as reducing health, quality of life and ability to work (Pankhurst *et al.*, 2020). Providing the right support during this complex period in a young person's life is, therefore, crucial. Such support needs to focus on the young person's wellbeing, not solely on using psychological interventions as a means to increase adherence to treatment.

Dallimore and colleagues (2018) explored why the transition from child to adult services is a dangerous time for young people with kidney disease. Their review of the literature identified evidence for four domains of transition needs and problems experienced by young people: social, developmental, psychological and health-related. Yet, despite the evident complexity, the authors note:

"There is a lack of research that takes a holistic view of specific transition needs and issues for young people with CKD [chronic kidney disease]. Well-being is mainly defined and measured from a clinical perspective and the transition process is often set out as a linear, one-dimensional conduit with individual characteristics, along with social, familial and societal relationships rarely being considered."

Campbell and colleagues (2016) conducted a Cochrane review of interventions to improve the care of adolescents with long-term health conditions as they transfer from child to adult health services. The review identified only four small studies covering a limited range of interventions. The authors concluded that there was insufficient evidence from which to draw firm conclusions, and they recommended rigorous evaluations with long-term follow-up. In addition to this gap in the literature, Dallimore and colleagues (2018) have highlighted the need for more research based on transition as

a multi-layered concept involving young people living with kidney disease, their families, health and social care providers and health and social care systems – all operating within a cultural, political and condition-related context.

Bearing in mind that recommendations can only be as good as the evidence on which they are based, in the same year as the Cochrane review was published, the National Institute for Health and Care Excellence (NICE, 2016) issued guidance for the transition from paediatric to adult services, which emphasises the importance of support that is developmentally appropriate, strengths-based and person-centred.

In thinking about what the ‘right support’ looks like, Gray and colleagues (2018) have identified the most commonly reported barriers to successful transitions along with suggestions for solutions, informed by a review of research conducted in the US focusing on children and young people with chronic illnesses (see Table 1).

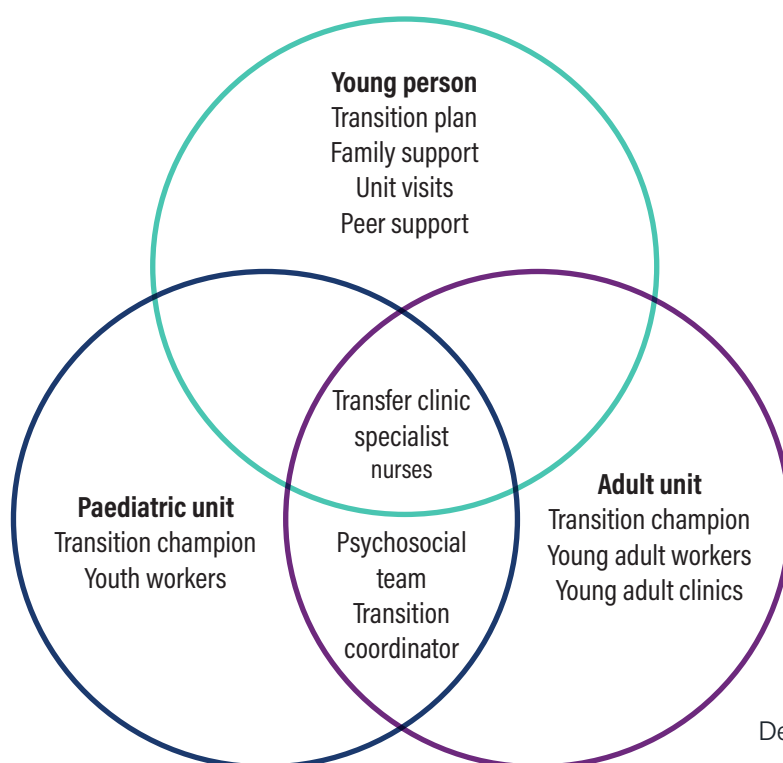
Table 1: Research-informed recommendations for successful transitions between paediatric and adult care, adapted from Gray and colleagues (2018)

Barrier	Solutions
Relationships	Allow patients interactions with adult providers before transfer Create joint clinic visits attended by paediatric and adult providers
Beliefs/expectations	Allow patients interactions with adult providers before transfer Create a structured transition plan or utilise Individualized Transition Plan templates Connect patients with peers who have already transferred Provide tours of the adult clinic
Skills/efficacy	Begin transition preparation in early adolescence Provide education on transitioning responsibility Encourage independent visits with the adolescent Use technology to target disease knowledge and other self-management behaviours Regularly assess and discuss transition readiness Improve coordination of care between medical teams
Access/insurance	Employ a transition coordinator Utilise a system or transition ‘navigator’ to help adolescents and young adults prepare for transfer and post transfer

Clementi and Zimmerman (2020) recommended incorporating transition planning through adolescence and young adulthood; that ‘transition readiness’ should be based on an individual assessment rather than a cut-off age; and that the transition should be gradual.

In 2011, the International Society of Nephrology (ISN) and the International Pediatric Nephrology Association (IPNA) made a consensus statement on the transition from adult to paediatric renal services (Watson *et al.*, 2011). It concluded:

“Transition from pediatric to adult renal services is an individualized process that provides the young person with appropriate self-management skills as well as assessing support structures. Since young people are in ‘transition’ from 14 to 24 years, it is vital that there be good communication between pediatric and adult services, especially at the point of transfer. Support for this age group should be developed on both pediatric and adult-focused sides. The consensus statements highlight developments that are necessary to ensure a successful health-care transition process.”



Department of Health, 2006

Families and carers

As discussed in an earlier section of this report, families and other unpaid carers play an essential role in the psychosocial support of people living with kidney disease. This is especially true for children and young people (Clementi & Zimmerman, 2020). Research has shown that, when a child has kidney disease, it has an impact on family dynamics and the relationships between all family members and that, to quote from one study, “the whole family constitutes a unit of care” (Agerskov *et al.*, 2020).

Families caring for children and young people with kidney disease face many sources of distress and they have a range of psychosocial needs.

Family members often experience overwhelming challenges, and there are gaps in the resources available to help them to cope (Wee *et al.*, 2022). The psychosocial needs of these families, identified in a focus group study with 21 parents, include information, emotional support and practical support (Geense *et al.*, 2017).

A suggestion is that the psychosocial needs of the whole family should be taken into consideration (Abrão *et al.*, 2021; Zhang *et al.*, 2023).

Having a 'normal' life

"Most dialysis units have patients who are over 50. But if you're a 16, 17, 18 year old, that's a fairly shocking place to spend three days of your week. Because not only are you around older people and it doesn't feel like it's your kind of thing, it's also that you can see, potentially, the trajectory of your life. I don't think we pay enough attention to that."

Two themes that stood out in our conversations with children and young people were the importance of play and of peers. Children and young people with kidney disease often spend a lot of time in medical environments. This comes at the expense of the time spent with friends and at school, meaning they have fewer opportunities for social interaction and for activities appropriate to their stage of life. One mother, whose young son is living with kidney disease, spoke to us about the struggle of balancing all his medical appointments against "mak[ing] time for him to be a kid."

Children and young people also spoke about the effect of kidney disease on their relationships. Their symptoms and treatments may make it harder for them to form friendships. They described living with kidney disease as "kind of isolating" and "[a] very lonely place". It could be especially difficult when their friends had little knowledge or experience of kidney disease. The children and young people who spoke to us said:

"You tell your friends and they're like, 'You're going to be fine, it's your kidney,' because to be honest, there is not much research, not much information about how important your kidneys are, especially when you are young."

"Friends only see you on good days, so they assume that you're okay. Kidney disease is a really hidden disease."

Because kidney disease is relatively rare among children and young people, those with a diagnosis are unlikely to meet others with a diagnosis outside of a clinical setting. This may mean they have fewer opportunities for conversations about their experiences with people their age who 'get it', compared to adults living with kidney disease.

"I always felt like kidney disease is stereotyped to the older generation. And sometimes I just feel that it's really emotionally draining to even explain that to my friends [...] so you just kind of hide it and go, 'Yeah I'm fine.'"

In our interviews and focus groups with children and young people, much more so than in those with adults, the importance of being able to talk to peers came up. One young person told us, "I have met someone [my age] with kidney disease before and I found that talking to them is really helpful!" This is echoed by Agerskov and colleagues (2020) who found, "Getting together with peer children with [kidney disease] resulted in a positive sense of belonging."

It may be important – even more so than for adults – to avoid psychosocial support taking the form of yet another intervention that takes place in a formal clinical setting, and to provide children and young people with opportunities to interact with people their own age who are living with kidney disease.

Accessing support

Children and young people face increased and different barriers than adults to being proactive in finding psychosocial support. They often lack the knowledge and the resources to be able to search for help independently. As a result, it's especially important that this information is visible in clinics (e.g. in the form of posters) and communicated to them by health care professionals.

"I've never seen any kidney leaflets about kidney disease at GPs or anything... I'm in my early 20s and I'm suddenly told that having a child might not be an option for me, or I might die younger [...] and there is no support afterwards, they kind of go 'here is all the stuff' and there is no real support network."

"Kidney health isn't something that I see talked about a lot or in the same way as other conditions might be [...] and that just adds to the lack of understanding and the scariness of that, I guess."

"Once you are able to access the support, it's amazing... but it's just being able to find out about the support."

Research has noted the importance of designing clinical pathways for children and young people living with kidney disease that suit their lifestyles (Harden *et al.*, 2012). The barriers faced by older young people may be connected to the way care is delivered. Many move frequently, if they are studying for qualifications or pursuing work experience. Some may spend part of their year in one location, another part somewhere else (on a university campus and at their family home, for example). They sometimes face a trade-off between continuity of care and convenience of location. Place-based support may be less appropriate to the needs of this age group.

Key points

The transition from paediatric to adult care is a time when having the right psychosocial support in place is especially important.

Children and young people are not just small adults. They have distinct needs, preferences and risk factors, which must be considered in their own right.

Kidney-specific psychosocial support

The people who participated in our focus groups and interviews identified a significant unmet need for psychosocial support in kidney disease. One person, speaking about their experience of psychosocial support, said: "I feel like it is non-existent," and another person described an "absolute lack of anything". Some regions have more resources available than others – the so-called 'postcode lottery' – but having some is not the same as having enough. Even those of our participants who had access to some psychosocial support through their renal unit reported that it was inadequate.

Some of the people we spoke to had experience of other long-term conditions, either personally as a patient or a carer, or professionally. This gave them an insight into the level of psychosocial support available to, for example, people with cancer. They described kidney disease as the "poor relation" in comparison.

When asked to imagine what good psychosocial care for people with kidney disease would look like, the one preference that was common to everyone who spoke to us in the focus groups and interviews was for kidney-specific psychosocial support. One person said:

"When I had [...] a cancer psychologist and a counsellor, I could see the difference that that made. They completely understood the disease, they completely understood what I was going through. I've had private counselling [...] but I found that I was having to explain so much to the counsellor to get her to even get where I was coming from. It was very difficult to break those boundaries, which I didn't have when I had a specialist counsellor."

Young people also described the difference it made, being able to talk to someone who understood their condition and its treatment:

"They [the renal youth worker] are much more friendly because they know me, and they know what I'm going through whereas the [non-specialist] counsellor that I went to before spent most of the time asking me and trying to figure out my condition, so I just felt like it's a waste of time."

"Having someone you can talk to about your condition [who understands it], that would be life changing [...] You kind of feel like there is someone else in your corner and it's not like another counsellor who is like, 'Oh right, okay what is [kidney disease]? What does it mean?'"

Key points

There has been little research into the outcomes of specialised vs. generic psychosocial support; and there is limited availability of kidney-specific psychosocial support (it is a 'postcode lottery'). Yet, the people who spoke to us had a strong preference for kidney-specific psychosocial support.

One size does not fit all


Some people have been living with kidney disease for as long as they can remember; others only develop problems later in life, often in connection to other long-term health conditions. Some people experience a gradual decline in their kidney function; for others this loss is sudden and unexpected. Some people are living with transplants; other people are on dialysis; and others choose to forego kidney replacement therapy. There is also great diversity among people living with kidney disease. It is not a condition that is confined to a particular group; it can affect any person at any point in their life. The strongest finding from our focus groups and interviews is that one size does not fit all when it comes to psychosocial care. People's needs and their preferences for support were as varied as their personal circumstances and experiences.

This finding is in line with other research. For example, Taylor and colleagues (2016), in a study of the preferences of people with end stage kidney disease for different approaches to psychosocial support concluded, "There was an overall variable and individualistic response to each approach." Damery and colleagues (2019) noted, "There is unlikely to be any single intervention that can support patients with distress – its incidence is largely unpredictable and its duration uncertain." And Shirazian (2019), after outlining the different pathways by which people living with kidney disease might arrive at depression, concludes, "This finding highlights the need to examine patient-specific interventions that target individualized behavioural and biological causes of depression."

In short, a system of psychosocial care designed for the 'average' patient will fail to meet the needs of many people. A person-centred, coproduced approach is needed.

The people who took part in our focus groups and interviews reported several assumptions that health care professionals had made about the psychosocial impact of kidney replacement therapies. One was that, because it is life-saving, they, as the people whose lives were being saved, either shouldn't or wouldn't have mixed feelings about the treatment. One person described the attitudes of the clinicians as, "It's just like: This is happening. This is the only thing that's going to keep you alive. So you've just got to deal with that."

Another assumption encountered by the people in the focus groups and interviews related to kidney transplants. Because kidney transplants are associated with the best outcomes, there is an expectation that the recipients will experience them as a straightforwardly good thing. This assumption leaves little room for the complicated and conflicting emotions around transplantation that are widely reported in the literature. For example: fear of transplant rejection; the loss of a community and a familiar-if-unwanted way of life, if the transplant marks the end of a long period of in-centre dialysis; changed body image; coping with the side effects of medication (and the status of being immunosuppressed while Covid continues to be a threat); the impact on the relationship with the donor, if they are a member of the family or a friend; sadness, if the kidney is from a deceased donor; dealing with the assumption among other people that a transplant is a cure; etc. (Jones *et al.*, 2020; Lonargáin *et al.*, 2017; McKeaveney *et al.*, 2022).



“As with patients with other chronic medical conditions, [kidney transplant] recipients describe significant “treatment burden” when caring for their transplanted kidney; treatment burden can cause fatigue, mental exhaustion, and impinge on prior social roles” (Nash *et al.*, 2022).

A further complication of the relationship between psychosocial and kidney health is an assumption by some professionals that: “The predominant objective of psychosocial interventions was behaviour change to increase medication adherence by improving the [transplant] recipient’s capability of managing their medication. Targeting adherence through self-management strategies and increased medication related knowledge implies the predominant psychosocial need of these recipients is one of organisation or education” (Wurm *et al.* 2022).

Key points

People’s needs and preferences are as diverse as their circumstances and their experiences. There is no ‘one size fits all’ solution for psychosocial support in kidney disease; an individualised approach is needed.

Person-centred care and coproduction

Morton and Sellars (2019) reviewed the development of person-centred care in kidney disease. They defined person-centred care as encompassing four distinct principles:

1. Care is delivered with dignity, compassion, and respect
2. Care is well coordinated
3. Care is personalised, taking into account clinical, social, emotional, and practical needs
4. Care enables people to take an active role in their own treatment.

Coproduced care not only focuses on the individual and their family and friends, but actively involves them as equal partners, sharing power with them and ensuring they play a meaningful role in decisions about how services are designed, delivered and evaluated (Vennik *et al.*, 2016).

Person-centred, coproduced care can help to reduce health inequalities and build trust. This is especially important to people who have had negative or traumatic interactions with health care services in the past, including people living with severe mental illness and people from racialised communities (Carswell *et al.*, 2022). Equally and oppositely, research by the Health Foundation (2020) has mapped some of the ways in which the lack of holistic, person-centred care can widen health inequalities by inflicting a disproportionately greater treatment burden on people who have multiple long-term conditions, especially those who are living in more deprived circumstances.

The people who spoke to us in the interviews and focus groups said there had been progress and that person-centred care and coproduction are more common in kidney care than they were 20 years ago, but there is still much work to be done. That there is room for improvement, at least in terms of coproduction, is demonstrated by the annual Kidney Patient Reported Experience Measure (PREM), which asks people living with kidney disease to score 14 aspects of their care. On each of the three years that the survey has reported its findings, 'Sharing decisions about your care' has received either the lowest, or the joint lowest, score (Kidney Care UK, 2022b).

Ramer *et al.*, 2018, found that health care professionals' perceptions of the priorities of older adults with kidney disease were correct only 35% of the time.

Shared decision-making typically goes hand-in-hand with a shift away from a disease-specific approach to care and towards a more goal-directed approach, led by a person's views and wishes for their life as a whole (Tinetti and Fried, 2004).

Shared decision-making rarely happens spontaneously. It is facilitated by a set of skills and values held by health care professionals, and requires people living with kidney disease to have access to adequate levels of information.

"I think coproduction is absolutely vital [...] We need to design it so that we're getting all voices in the room, and also so that it's not tokenistic."

Research into shared decision-making with younger people living with kidney disease is more limited, but initial findings indicate that it is associated with positive psychosocial outcomes (Kerklaan *et al.*, 2022).

It has also been noted by researchers that positive outcomes have to be defined by young people and families themselves – not imposed by professionals: “Although research to better understand patient and family-prioritised outcomes continues to progress, life participation has emerged as a core outcome. Yet, life participation can have various meanings and represent an array of values depending on the child and family. A deeper exploration of what it means to fully participate in one's life is needed” (House and Wightman, 2023).

Mohottige and colleagues (2021a) discuss the importance of ‘centring at the margins’: “Centering at the margins is an important part of antiracist process whereby the perspective of a marginalized group becomes ‘the central axis around which discourse occurs’.. Centering at the margins requires creating non-hierarchical opportunity for patient and community engagement, thus yielding invaluable contextual data and expertise.”

Tramonti and colleagues (2021) have highlighted the ways in which systems thinking and integrating biological, psychological and social support can advance the objectives of person-centred care:

“Individuals are inextricably connected with significant others, and studies on health and quality of life confirm that relationships are crucial aspects of well-being. There is no such thing as individual well-being outside a relevant context, and developing the greatest accuracy in the evaluation and promotion of positive relationships within families, groups, healthcare settings and communities is a fundamental goal.”

It is important to note that different people will have different preferences for their involvement in their care. Some people may find the responsibility burdensome and anxiety-provoking, rather than empowering. Their choice may be for minimal involvement in decision-making. However, what matters is that it is a choice, and not the default assumption of the health care team.

Key points

Person-centred care and coproduction can mitigate some of the negative impact of kidney disease treatment on psychological wellbeing. They can also help to ensure psychosocial care meets the needs of the people it is intended to support.

Stepped care, screening and assessment

People's level of psychosocial need exists on a spectrum from low to high. On average, the level of need for people living with kidney disease is likely to be higher than that of the general population. Nonetheless, there are different levels of need which require different levels of support within the population of people living with kidney disease .

This report has discussed some of the risk factors for higher levels of psychosocial need. For example, in general, transplants are associated with better psychosocial outcomes (Fletcher *et al.*, 2022; Purnell *et al.*, 2013; Tonelli *et al.*, 2011). However, while this is true, it conceals the variation within the group. Some people who have received a transplant will cope well, but others will have severe and complex psychosocial needs. This is true for all populations of people living with kidney disease. It is rarely possible to predict an individual's needs with any degree of accuracy from demographic factors or factors relating to kidney disease alone; some form of individual assessment is needed. Moreover, people's needs aren't static. The same person may be coping more or less well at different points in time; regular assessment and follow-up is needed.

Stepped care

According to NICE (2022), stepped care is a system of delivering and monitoring treatments so that the most effective, least intrusive and least resource-intensive treatments are delivered first. It is a pragmatic response to limited resources, which helps to direct the most time- and expertise-intensive approaches to those with the greatest need. An example of stepped support for people living with cancer (NICE, 2004) can be found [here](#). A similar model developed for diabetes care (Sachar *et al.*, 2020) can be found [here](#).

However, there are caveats to this broad-brush approach (Cross & Hickie, 2017). For example, in some stepped care models, people's ability to move between steps as their needs change or conditions deteriorate can be limited if they are too inflexible, as has been noted in Children and Young People's Mental Health Services, for example.

Stepped care models also only work if every step is sufficiently resourced according to levels of need.

Another challenge for stepped care is designing a model that is intuitive and efficient – that's to say, one that doesn't require a large amount of training and time to use – while also being able to accommodate the complexity of people's circumstances. For example, research has identified at least two dimensions of psychosocial need (emotional and practical), and each of these exists along spectrums ranging from acute to chronic, routine to urgent, simple to complex, etc. One approach to capturing this complexity in a single model is provided by Coyne and Fretwell (2022). Their integrated model for renal psychosocial support is adapted from an existing cancer psychosocial support pathway.

However, models of stepped care, no matter how conceptually well-worked out, are only of academic interest if they are preceded by accurate screening and assessment, and if the care pathways they refer to are in place. From the perspective of the person in need of support, what matters most is that they are allocated to the right 'step' of the model at the right time, and that this step connects them to care that makes a positive difference to the difficulties they're experiencing.

Identifying psychosocial needs

There is no formal screening and assessment programme for psychosocial needs in kidney care in the UK. Generally, the expectation is that GPs, dialysis staff, or other renal clinicians will pick up on signs of distress, and will either provide general psychological support themselves, or refer patients to colleagues who have additional expertise for assessment. Pearce and colleagues (2022) found that depression was most commonly identified among kidney patients through validated screening tools such as the Beck Depression Inventory.

However, research has identified several barriers to renal staff recognising signs of distress. These are:

- Renal unit organisation
- Staff prioritising, or having a preference for, medical care
- Lack of time
- Lack of training or skills
- Difficulties identifying distress unless directly expressed by patients
- Not knowing how to respond to distress
- Fear of getting too involved or saying the wrong thing
- Perceptions of responsibility
- Negative emotional impacts on staff
- Lack of services for onward referral.

(Combes *et al.*, 2017; Damery *et al.*, 2019)

There also remains a persistent stigma to disclosing psychological distress and a fear of what this might mean for an individual. This may be especially acute for people from racialised communities, for whom effective and trusted mental health support is less readily available, and for older people.

Going into more detail about the way in which people living with kidney disease may anticipate some of these challenges, Damery and colleagues write:

“[M]any patients reported that they deliberately hid distress to avoid burdening healthcare staff who were perceived as being under stress themselves, too busy carrying out clinical tasks, or with limited time to discuss emotional issues. Some patients also felt that talking about emotions with staff on the renal unit was inappropriate, believing that staff would not understand their situation or that they lacked the relevant skills to handle any emotional issues raised. Patients who attended the renal unit infrequently – such as those on home therapies or who had received a transplant – reported limited opportunities to raise emotional issues, which added to their reluctance to disclose distress when they did attend the renal unit.”

Similar findings have been reported by Sein and colleagues (2020) who interviewed people with kidney disease at four hospital trusts about their emotional distress and adjustment to end-stage kidney disease. Some of their participants spoke about hiding their emotions from health care staff, and purposefully putting on a more positive front. Reasons included: not wanting to be seen as complaining about their treatment; a perception of dialysis staff as too busy to talk about anything but the practicalities of their care; and a perception that it wasn't the role of dialysis staff to listen to the emotional side of patients' experience. Also, the dialysis environment and its lack of privacy added to the feeling that it wasn't an appropriate place for conversations about emotional issues (on the topic of privacy, see also Schick-Makaroff *et al.*, 2021). In short, relying on renal staff to pick up on the psychosocial needs of people with kidney disease in an informal and ad hoc way is an unreliable approach, which is likely to result in people's needs being missed.

An alternative is a formal and regular programme of psychosocial assessment. Sachar and colleagues (2023) have assessed whether such a programme would be feasible for, and acceptable to, renal health care professionals and people living with kidney disease. The study used two screening instruments: the Patient Health Questionnaire-4 (PHQ-4), covering anxiety and depression; and the Distress Thermometer, which can be used to facilitate a discussion about the causes of the distress (e.g. practical, family, emotional, spiritual, physical, etc.). The study then combined the scores from these instruments and used a 'traffic light' system to determine the next steps. Accompanying this system was clinical signposting advice corresponding to each of the three levels, and tailored to cover locally available services.

In addition to 'how?', other questions for screening programmes are 'when?' and 'where?'. The same study provides preliminary answers: Sachar and colleagues (2023) note:

"Most renal [health care professionals] and patients felt that the screening should take place at the point of diagnosis, as well as at the point of any worsening of renal disease and annually. Both HCPs and patients felt that the questionnaires could be completed in the waiting area before seeing the HCP"

This finding adds weight to the following recommendation from the manifesto from the National Psychosocial Working Group (2022):

"All kidney patients to have their psychosocial needs assessed using validated methods

1. At diagnosis
2. As they change treatment
3. As they go through different stages of kidney disease
4. At times of distress
5. Annually."

Although as discussed above, the overlap between kidney disease symptoms and mental illness symptoms adds complications to screening, these complications can and have been overcome. Research has shown that a range of screening instruments have good sensitivity and specificity for identifying risk (e.g. Dano *et al.*, 2022)

Chilcot *et al.*, 2018 have validated a screening measure for psychological distress in people receiving haemodialysis. The measure can detect mixed symptoms of anxiety and depression that are below the threshold for clinical diagnosis. This captures important dimensions of psychosocial needs, but does not give the full picture.

Given the limited availability of staff and the already high treatment burden of people living with kidney disease, lengthy assessments, it could be argued, are in no one's best interests. However, a rapid and pragmatic approach is likely to be a reductive one – i.e. an approach that uses a quick and well-established proxy for psychosocial need, such as a validated depression scale. It's important that, even if the complexity of psychosocial need gets missed out of the screening stage, it gets put back in at a later stage, if people living with kidney disease are to receive effective support.

As Goh and Griva (2018) point out: "It would also be important to more broadly consider the spectrum of emotional experience including anxiety, worrying, fear of progression of kidney disease, and fear of the future in general, demoralization, death and dying, hopelessness, questions around the meaning of life, and the experience of recurrent psychological and physical trauma through the disease trajectory, just to name a few."

Key points

At its most basic, good psychosocial support involves having a range of options suitable for different levels of need (stepped care), and mechanisms for ensuring that people are matched to the option most suitable to their level of need (screening and assessment).

Working pre-emptively and proactively

When someone receives a diagnosis of kidney disease, they are likely to be encouraged to make lifestyle changes that will help to slow the progression of their condition and give them the best chance of good medical outcomes. Typically, these changes focus on diet, exercise and other health behaviours, such as stopping smoking and reducing alcohol intake. Kidney Research UK's Peer Educator Initiative (see Box 1) is an example of support for these purposes, among others.

As outlined above, there is a wealth of evidence linking psychosocial wellbeing to medical outcomes and it is fundamental to living well with kidney disease (there is 'no health without mental health'). Yet, typically, psychosocial support is not included among the early interventions that people living with kidney disease are informed about or offered. This is despite a growing body of evidence that preventative measures, at least in the general population, are feasible, safe and cost-effective (Arango *et al.*, 2018; De Pablo *et al.*, 2021). A systematic review found, for example, that cognitive behavioural therapy (CBT) had a significant effect on depression symptoms among people living with kidney disease, while the benefits of antidepressant medication were found to have limited evidence (Pearce *et al.*, 2022).

In our focus groups and interviews, people told us that they received no support in maintaining or strengthening their psychosocial wellbeing. Instead, it wasn't until they became sufficiently unwell to meet the diagnostic criteria for a mental health issue, such as depression or anxiety, that they were offered help. And, by that point, it was too late for low level pre-emptive and proactive interventions; more specialised, resource-intensive care was needed. One person living with kidney disease said:

"You have to be in crisis to actually get that support. You do have to be in crisis, and then you have to have the right person connecting people, and it is a lottery."

This was echoed by health care professionals who described a sense of inevitability among renal staff about the psychological impact of adjusting to life with kidney disease, and a lack of psychosocial preparation for kidney replacement therapy:

"There's going to be a lot of, 'Well, it's normal to feel like this,' But, it's a weird thing: 'It's understandable that I would feel like this with this diagnosis,' but [clinicians] not being able to translate that into, 'But there is help [...] to be able to process this.'"

"I think many of [the people starting dialysis] arrive there in a state of shock, and I think that's a real problem in terms of how they subsequently deal with that. And I think [...] there's a real dearth of adequate preparation for the rigours of what they're about to receive."

One health care professional, summing up the state of psychosocial care in their renal unit, said:

“Most of the work is reactive. We are constantly firefighting.”

The experience of renal staff and people living with kidney disease alike is that, between coping well and being in significant distress, there is often very little psychosocial support available.

To address this gap in pre-emptive and proactive care, interventions have been developed and evaluated. For example, Carswell and colleagues (2020) conducted a feasibility study of an arts-based intervention for people receiving haemodialysis. Greenwood and colleagues (2021) conducted a randomised control trial of an exercise programme, again for people receiving haemodialysis. Improving Distress in Dialysis is a tailored cognitive behavioural therapy (CBT) intervention targeting factors relating to distress in kidney disease (Hudson *et al.*, 2016). Another example is CBT for renal fatigue (Picariello *et al.*, 2018). And a Cochrane Review concluded with moderate certainty that cognitive behavioural therapy (CBT), exercise and relaxation techniques probably reduce depressive symptoms in people receiving dialysis (Natale *et al.*, 2019). There has also been an expansion of digital interventions, most significantly with the UK-wide launch of Kidney Beam in 2020, which is described in more detail in Box 2.

Box 2: Kidney Beam

Kidney Beam (a research trial supported by Kidney Research UK) was developed to support people living with kidney disease to stay physically active and emotionally well during the Covid-19 pandemic. It is an online platform that provides access to programmes, live and on-demand classes, and community and motivational support. Classes include: movement, arts, sleep, goal setting, education and nutrition advice.

The Kidney Beam for Kids online platform is currently being trialled and is in the recruitment stage, aimed specifically at children.

During the initial six-month pilot study in 2020, 959 adults signed up, and 43% proceeded to complete one or more classes. The biggest reported benefit was that the intervention was kidney-specific and delivered by specialist kidney health care professionals (Mayes *et al.*, 2022).

However, research has highlighted a number of barriers to pre-emptive and proactive psychosocial care for people living with kidney disease. One is resources, especially the availability of staff. In their study of the role of the renal social worker in the UK, Seekles and Ormandy (2022) wrote:

“The focus of [a renal social worker] is on offering pro-active and preventative support, yet this is impeded by inappropriate staffing levels, in combination with high volumes of often crisis-driven referrals.”

To create more capacity for pre-emptive care, Farrand and colleagues (in press) have outlined a competency framework for the role of a renal assistant wellbeing practitioner, which would focus on evidence-based approaches for preventing mental health problems. But, in the context of staff shortages and tight budgets, it is unclear whether this proposal will be viable.

Another barrier to pre-emptive and proactive psychosocial care is the digital divide. Digital interventions typically make fewer demands on resources and staff time which, in light of the previous

point, make them an attractive proposition. But, as Graham-Brown and colleagues (2022) note,

“[T]he characteristics of individuals who tend to have lower digital literacy and access are the same as those who are marginalised by traditional health inequalities, i.e. lower socio-economic status, increasing age, minority ethnic background and lower educational attainment.”

Therefore, if psychosocial support is to be delivered digitally, it needs to go hand in glove with providing people with the skills and technology to access it, otherwise it may simply widen existing inequalities. Research on the delivery of remote and digital mental health care more generally has also indicated that people’s individual preferences for either remote or in-person support must always be honoured, with adaptations provided where necessary to facilitate equitable provision (Centre for Mental Health, 2022).

A third barrier to pre-emptive and proactive psychosocial care is demand. The people who spoke to us in interviews and focus groups were clear that they would have welcomed and benefitted from support at a much earlier stage. But it’s important to note that they were not a random sample. Many had been living with kidney disease for a long time. And many, when speaking about their motivation to participate in the research, said they wanted other people to receive the support they wished they’d had. But what about those who are at an earlier point in their experience of kidney disease and who do not have the benefit of hindsight? Are they equally clear-sighted about the potential advantages of engaging with pre-emptive and proactive care?

An answer is suggested by the high number of people with kidney disease who either decline to take part in trials for psychosocial interventions, or who agree to participate but then drop out. Many studies of pre-emptive and proactive support report difficulties with recruitment and retention (Carswell *et al.*, 2020; Greenwood *et al.*, 2021; Hudson *et al.*, 2017; Thompson *et al.*, 2016).

Reasons may include that kidney disease has a heavy treatment burden: some of the psychosocial impact of living with kidney disease is to do with life becoming an endless round of medical appointments and treatments; so if psychosocial care takes the form of yet another medical appointment, it risks becoming part of the very problem it’s seeking to address.

Opportunities for earlier help may also be missed where people are not yet receiving support from specialist renal services. As Graham-Brown and colleagues (2022) note, “most patients with earlier-stage CKD [chronic kidney disease] are managed in primary care, where there is limited or no access to services for patients with CKD relating to lifestyle or patient education.”

Evidence indicates that, with kidney disease, it is a person’s perception of their illness, more than their actual symptoms, that predicts their psychological wellbeing (Knowles *et al.*, 2014). This suggests that interventions targeting illness perceptions – organised beliefs about symptoms, consequences, time course, controllability and causes of an illness – are promising targets for intervention (Chilcot, 2012).

NICE (2021) guidance for the assessment and management of kidney disease recommends offering adults “high-quality information or education programmes as appropriate to the severity of their condition to allow time for them to fully understand and make informed choices about their treatment”, and recommends that these should take account of the psychological aspects of coping with kidney disease and offer patients access to support groups, counselling or a specialist nurse.

In the 2021 Patient Reported Experience Measure (PREM), 24% of people who responded to the survey gave a poor score to whether their renal team asked them about their emotional feelings, and 14% said this was something their team never did (Kidney Care UK, 2022).

In summary, it is vital that psychosocial support should be available to everyone, not only those who meet the threshold for a clinical mental health diagnosis or who qualify for specialised social care, but it must be offered in ways that are engaging and equitably available.

Key points

Pre-emptive and proactive psychosocial support is better for patients and it is better for services. Information and education programmes may help people to maintain their mental wellbeing as well as their physical health.

Multidisciplinary working and joined-up care

A multidisciplinary team is a group of health and care staff who belong to different specialisms and professions who work together to support individual patients (NHS England, 2022). Joined-up care is person-centred and coordinated within health care settings, across mental and physical health, and across health and social care (HM Govt, 2014).

Two people who participated in the focus groups and interviews spoke about good experiences of joined-up care. In both instances, they gave the whole credit to particularly diligent nurse practitioners who took personal responsibility for coordinating different aspects of their care.

“Luckily, there’s a very proactive nurse practitioner there [at the renal unit] who’s brilliant, and she connected the people together. But if it wasn’t for that, I wouldn’t have had that support.”

More commonly, people spoke about experiencing a “disconnect between the clinicians and the psychological support”. One young person said, “I suffer with bad mental health outside of having kidney disease and they [the health care professionals] don’t look at those things side by side, although each affect each other.” Other young people noted the lack of follow-up: they mentioned that seeing their doctors often left them feeling worried and concerned, but no one contacted them after an appointment to make sure they were okay.

Box 3: Ali’s experience

I had an interesting experience with the living donor team at my renal unit. Me and my husband went into the UK Living Kidney Sharing Scheme for the first time a couple of months ago, and got a call to say that we’d been matched. And we were like, wow, okay, that’s amazing, because it usually takes a couple of tries before you get a match, and they were talking about what would have to happen, which would be a call that me and my husband would have with the Human Tissue Authority [HTA] to make sure that no one was being pressurised into donating. That went ahead and the HTA were happy for us to be involved in the match. And then, basically, radio silence and it felt like the only time we heard from the Living Donor team was when we contacted them.

About two months after originally getting the match, we asked the renal team at my hospital to follow up with the Living Donor team on our behalf, which they did. They came back later that day and they said, ‘Oh, sorry, it’ll be next month.’ Then about three days later we received a call to say that unfortunately one of the other recipients was no longer well enough to have an operation so the match couldn’t go ahead.

So we went from potentially having a transplant this year to... well, that was quite tough. And I’ve noticed there’s not much joined-up thinking. You have to be your own advocate and tell everybody. You know, I would’ve liked for the Living Donor team to have contacted Amy, who’s

my renal counsellor, to say, 'Oh, Amy, just to let you know, Ali's found out that she's not going to have this transplant that she's been hoping for for the last couple of months and that she's put her life on hold for. Maybe, you know, you could you give her a call?'

It would've been really lovely the day after I found out that I wasn't going to have a transplant for Amy to have phoned me and said, 'Hi Ali, I've heard what's happened. Do you want to talk now? Do you want to come and see me? Shall we bring forward our next session?' That would've really helped.

Ali's experience shows how people living with kidney disease are often left shouldering the burden of joining up the medical and psychosocial aspects of their care.

This responsibility is multiplied for those who have additional health conditions. In a focus group, someone who was living with two long-term illnesses said:

"I guess I just felt lost as a patient among all the specialities involved."

Multidisciplinary working and joined-up care are written into frameworks and guidelines for kidney care. At least one year before starting dialysis, all kidney patients should be referred to a multiskilled renal team for clinical and psychological preparation (Department of Health 2004 & 2005). Some have also recommended that this team should include a psychologist, a counsellor or psychotherapist, a social worker and a youth worker (British Renal Society, 2020; Seekles *et al.*, 2020). However, the gaps and discontinuities in support reported by people in the focus groups and interviews indicate that multidisciplinary working and joined-up care are not yet functioning as they should.

There is evidence to support the inclusion of dedicated psychosocial support in the renal care pathway (Seekles *et al.*, 2020).

Box 4: An integrated care model for mental health in diabetes

Diabetes UK and NHS England convened an Expert Working Group to develop a model for integrating mental health care pathways with diabetes care pathways. The recommendations were designed to apply across all services and all demographics, although the authors note some may need to be adapted for paediatric care.

The five core principles are:

1. Care for all people with diabetes explores what matters to them and emotional wellbeing is supported at diagnosis and beyond
2. People with diabetes are signposted to information and peer support and referred to education
3. People with diabetes have their emotional and mental health needs identified and acted on
4. People with, or at risk of, diabetes who are accessing mental health support in a specialist or primary care setting have diabetes considered within their care
5. People with diabetes have access to care from diabetes specialist mental health professionals.

The overarching vision is one in which support and care for people with diabetes is delivered by a multidisciplinary team, and may involve services across primary and secondary care including those from diabetes, mental health, general practice, emergency care, social care, substance misuse, learning disability, memory, eating disorder and other services. People affected by diabetes have input into local service development, and have choice and control over the way that care is planned and delivered. It is based on 'what matters' to them and their individual strengths and needs.

For more details, see Sachar and colleagues (2022).

Key points

There are gaps in the systems resulting from a lack of communication, coordination and integration within and between teams and specialisms. These gaps have a negative impact on patients' wellbeing.

The need for psychologically informed kidney care

An earlier section of the report discussed the importance of 'kidney-informed' psychosocial care, in which emotional and practical support is provided by people who have an understanding of kidney disease. Equally, there have been calls for renal clinicians to have an increased awareness of psychological wellbeing and mental illness (Alshelleh *et al.*, 2022; Alwar & Addis, 2022; McKeaveney *et al.*, 2022). That is to say, it is not enough to have psychosocial professionals within a multidisciplinary team. All team members need to hold enough understanding of psychosocial needs to be able to work in a psychologically informed way, and this understanding needs to underpin all interactions, including those with unpaid carers and potential kidney donors.

Psychologically informed means being aware of people's psychological needs and being able to recognise signs of distress. It also means being able to respond to these needs in a supportive way, where necessary putting a person in touch with a service or a professional who can offer an appropriate level of care. Being psychologically informed isn't limited to mental health. It encompasses neurodiversity, learning differences and cognitive impairments. And it may include, for example, if a patient is behaving disruptively, helping staff to reflect on what could be driving the behaviour, rather than simply labelling it 'non-compliance'.

The lack of psychologically informed care has a range of negative consequences. Foye and colleagues (2020) wrote:

"[T]he delegation of mental health care to other teams or staff not working as core members of the ward team creates complicated care pathways, additional workload for ward staff and reinforces a belief that patients' mental health needs can be seen as entirely separate to their physical health care."

And De Jong and colleagues (2021) describe how, when renal professionals focus on the medical aspects of a person's condition at the expense of perceived wellbeing, it can damage the therapeutic relationship, resulting in feelings of frustration and alienation among people living with kidney disease. This frustration was expressed by one of the young people who participated in our focus group:

"I can't recall one session where the medical doctor asked how I'm feeling mentally. It's just, 'Your kidneys aren't good, we are going to tackle your kidneys.' [...] So you're sent off without knowing what to do next."

There are several preconditions to being able to work in a psychologically informed way. One is training and skills. In our focus groups and interviews, people working in renal services and people living with kidney disease described variable levels of psychological awareness among staff.

However, it's one thing to not have the requisite skills, and it's another to have the skills but to face barriers to using them. One focus group participant said:

"I actually think that the awareness of mental health from the medical team, from the multi-disciplinary team, is actually very high. Whether they have the capacity to actually always deal with what they know is going to be an issue."

Workforce shortages, long hours and high workloads are taking a toll on NHS staff; many are overstretched and under sustained pressure (Deakin, 2022). And, as one of the health care professionals who spoke to us noted, "The mental health burnout of the staff is another issue that makes it harder for them to bring their whole compassionate selves."

The lack of care pathways for onward referral may compound these issues. One focus group participant mentioned how the willingness of staff to ask about psychological wellbeing can be "tempered by a feeling of [...] impotence about what you can do about it." They went onto say:


"I think there's a kind of, 'I don't want to dig into this too much because what will I do then?' So there is an issue about going looking for trouble if you're going to be left holding the baby on your own really."

It is difficult for someone to work in a psychologically informed way if they are not being supervised and managed in a psychologically informed way. Psychologically informed thinking needs to be present at every level of the health care system if it is to be effective. Foye and colleagues (2020) make the following recommendation:

"There is a need for staff to be supported from the top-down, with management providing clear leadership around issues and pathways for mental health so staff know the best way to provide care and encourage collaborative working. In addition, bottom-up support is needed to help staff personally manage their own well-being and mental health, including supervision, debriefing and role modelling from [mental health nursing] specialists to improve understanding of the patients' perspective and to provide emotional support when managing difficult situations. In our view, simply bolting-on staff training will be insufficient to bring about significant change."

The barriers identified here to psychologically informed working are similar to those discussed by Damery and colleagues (2019). They write that the ability of renal unit staff to provide emotional and psychological support effectively "may be mediated by issues such as staff education and training, perceived role and capacity, confidence, time, knowledge about options for onward referral of distressed patients, and the degree to which managing distress is considered by an individual to be their own responsibility, or the responsibility of others."

Coyne and Fretwell (2022) discuss how psychosocial specialists within a renal team can share expertise across the whole pathway, playing a key role in promoting and supporting psychological awareness among members. In dialysis units in particular, staff often build up close relationships with patients over time, and compassionate communication has much value.



“The need for closer integration does not imply that staff need to become experts in the area of mental health but rather require support and resources to feel competent and confident in delivering care for this patient group” (Foye *et al.*, 2020).

Key points

Psychosocial support, when done well, is not just an add-on to kidney care, but a strand that runs through every part of it.

Resources

“It’s an inability to resource what we know needs to be done to look after patients’ mental wellbeing, their psychological wellbeing, and we can’t just expect our nurses to be able to pick everything up.”

The previous sections have outlined why psychosocial support is essential. They have also set out key elements of this support. Some of these elements would need existing resources to be reallocated; others would require additional investment. This is a challenging proposition in a context where tight funding and staff shortages are widespread. Yet other long-term conditions which may be further along the path to good psychosocial care, such as diabetes and cancer, demonstrate that it is possible.

Workforce

“You can’t own a problem that you just don’t have the capacity to deal with. We need to be increasing the capacity of the renal service to own this problem.”

Based on data collected in 2017, Seekles and colleagues mapped the UK renal psychosocial workforce (2018 & 2019). They found that, although overall the renal psychosocial workforce had grown, it had not kept pace with the growth in the number of patients. There were inequalities and large variations in the number of staff available in different units. They concluded that the number of psychosocial staff was too low to meet the needs of all the patients with kidney disease.

In subsequent work, Seekles and colleagues (2020) found that people attending renal units with higher ratios of psychosocial renal staff to patients were less likely to experience distress even when controlling for demographic differences. The same study also indicated that the type of psychosocial support matters: people attending renal units with both practical support (as provided by a social worker or welfare advisor) and emotional support (from a psychologist or counsellor) were significantly less likely to want additional support, compared to those who attended units with a more limited range of support. These findings strengthen the case for the inclusion of dedicated psychosocial support in the kidney care pathway. Moreover, it was recommended that this support should include a psychologist, a counsellor or psychotherapist, a social worker and a youth worker (Seekles *et al.*, 2020). The workforce plan of the British Renal Society (2020) goes into greater detail about this, mapping the different psychosocial roles within the multidisciplinary renal team and proposed staffing levels.

In addition to dedicated psychosocial professionals, this report has highlighted the importance of psychologically informed support across the whole kidney care pathway. As discussed in the previous section, training for the renal workforce has an important role to play in making this possible, but it

is not enough on its own. For staff to be able to use their skills, they need time and support (Combes *et al.*, 2017). That means having access to psychosocial expertise and supervision, not being over-stretched and burnt out, and having managerial support to prioritise psychosocial concerns. As one health care professional said in the focus group:

"I think part of the solution to, if you like, not being able to monitor someone's mental health is the structure of jobs for people in units, because they don't get time to reflect, they don't get time to engage..."

None of these objectives will be easy to fulfil in the current climate. But they are not all-or-nothing; each step towards them will be movement in the right direction.

Finally, the current postcode lottery for psychosocial care has widened inequalities. Among those who are living with kidney disease and who need psychosocial support, some will receive this through their renal unit. Others will take on the additional treatment burden of searching for private support. And many, who can't afford to seek private support, will go without. National standards for access to psychosocial and psychologically informed support are needed, including what expertise should be available where and when, and at what levels.

Funding and culture

The NHS is facing rising cost pressures (The Health Foundation, 2023). When funds are tight, commissioners are under increased pressure to prioritise investment in 'core' aspects of kidney care; and, traditionally, this has meant more conventional medical treatments and staff.

The evidence presented in this report demonstrates that, contrary to what has been understood previously, effective psychosocial support is a core aspect of kidney care. Good psychosocial outcomes matter deeply to people living with kidney disease. They are also related to good medical outcomes, and they may be related to cost savings (Naylor *et al.*, 2012).

But, for psychosocial support to receive a level of investment that reflects its importance to people living with kidney disease, and to other crucial outcomes, there needs to be a change in culture (Combes *et al.*, 2017).

Increasingly, health charities are pushing for this change. In recent years, there have been a range of campaigns and reports highlighting the crucial importance of psychosocial care to people with long-term physical health conditions, including much good work focusing specifically on kidney disease (Coyne & Fretwell, 2022; Diabetes UK, 2019 National Psychosocial Working Group, 2022a).

Key points

Psychosocial support will continue to be inadequate until it is recognised as being a core component of good care for kidney disease, and is funded and staffed accordingly.

What have we learned and what needs to happen next?

Good psychosocial care is necessary to improve a range of outcomes in kidney disease. It's associated with better adherence to treatment, increased ability to self-manage, improved medical outcomes and better quality of life. Above all, it matters to people living with kidney disease (Carter *et al.*, 2020; González *et al.*, 2020; Hanson *et al.*, 2020; Natale *et al.*, 2019; Tong *et al.*, 2008; Urquhart-Second, 2016).

As other research has noted, the crucial question is although people are living longer with kidney disease, are they living well with kidney disease (Clementi & Zimmerman, 2020; Kalantar-Zadeh *et al.*, 2021)? There is clearly growing recognition of the significance of this issue, but it has yet to make a sustained impact on day-to-day practice in renal services consistently across the UK and for all groups of people.

It is important to note that not all people living with kidney disease will experience psychosocial distress. And not all of those who do will want to access support for it. This is consistent with research on other long-term conditions (Centre for Mental Health, 2021). But it is also clear that the need and demand for psychosocial support outstrips what is currently available in most places.

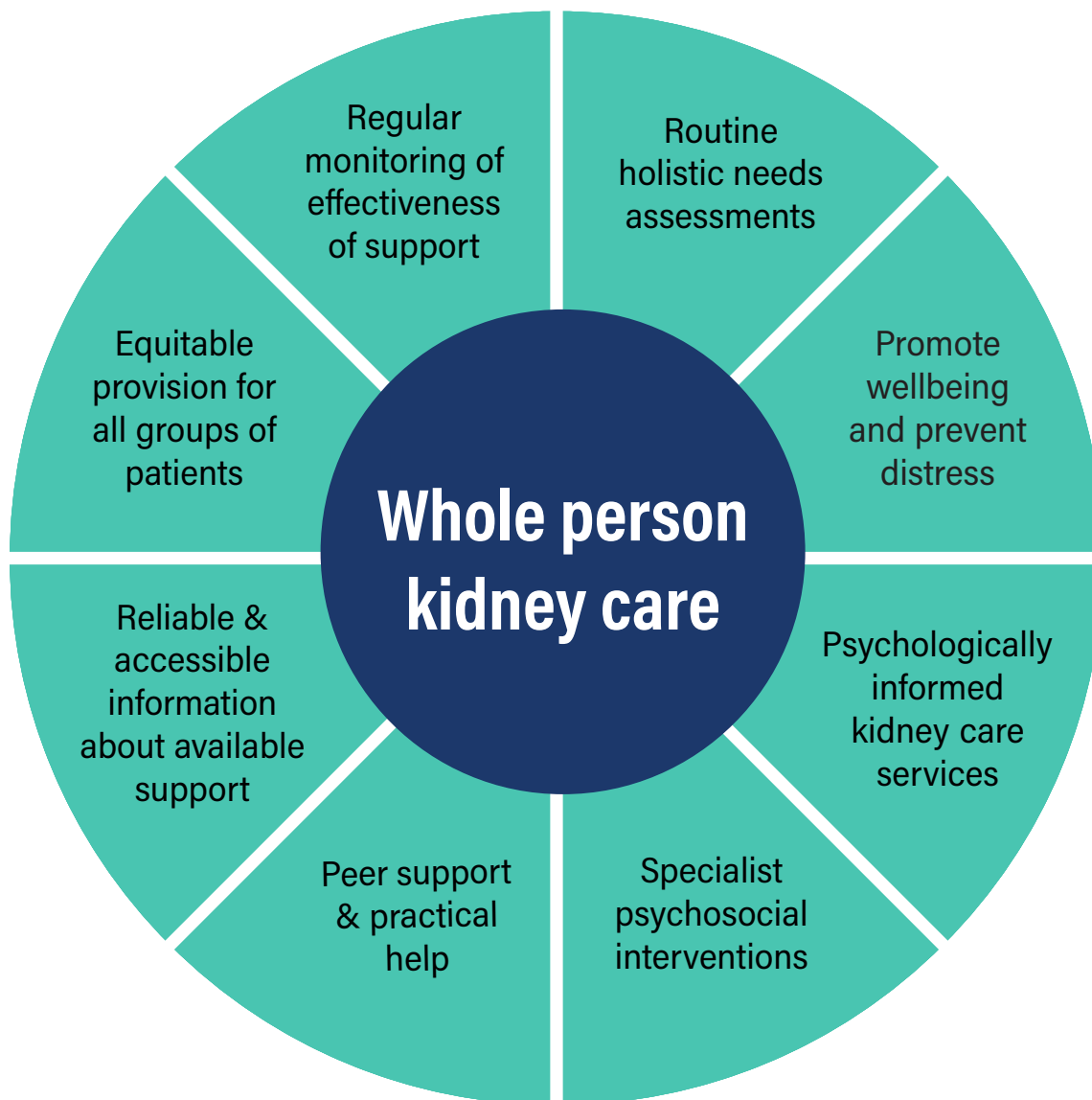
Among the people who participated in our focus groups and interviews, several had experience of kidney care spanning decades. They observed that awareness of the psychosocial impact of kidney disease had increased over time, which was to be celebrated. However, they also emphasised that the pace of change was too slow, relative to the scale and the impact of the problem. More psychosocial support is available than 20 years ago; but what is available is far from sufficient to meet people's needs.

There is no single addition or intervention that can meet people's psychosocial needs across the board and close the current gaps in support:

"Bridging this gap is unlikely to be achievable through simple interventions – patient distress often has complex roots and influences, and staff experience numerous challenges in being able to identify distress and respond effectively. The complexity of these issues suggests that any modifications to service organisation and delivery would need to be multi-faceted, encompassing changes at both the organisational (unit) and individual (staff) levels to improve patient education, enhance staff skills, implement changes to available support options, and facilitate changes to renal unit culture." (Damery *et al.*, 2019)

We have developed a model (Figure 1) for holistic stepped care for people with kidney disease that emphasises the importance of all elements of support being offered flexibly according to people's needs and equitably across all groups of patients. The model draws on the essential elements of psychosocial care identified in this report.

Figure 1: Whole person kidney care



Additional considerations

While beyond the scope of this report, there are a number of other issues that affect the mental health and psychosocial needs of people with kidney disease. These include:

- Cognitive impairments, dementia, eating disorders (which are more common among people with kidney disease), neurodiversity and learning difficulties
- The value of exercise, physiotherapy, occupational therapy, and educational interventions, all of which are likely to improve the health-related quality of life of people living with kidney disease (Wilkinson & Smith, 2021; Boonstra *et al.*, 2022; Schrauben *et al.*, 2020)
- The specific needs of people living with kidney disease who also have one or more additional long-term condition (Hawthorne *et al.*, 2023; MacRae *et al.*, 2021). The long-term goal should be a system that is equipped to cater for this complexity
- For the most part, this report generalised ‘kidney disease.’ However, different paths to developing kidney disease and treatment (e.g. genetic conditions, sudden and unexpected entries to treatment), and different types of treatment (dialysis, transplant, conservative care) are not all equal in terms of their psychosocial impacts. These differences need to be considered in the provision of effective psychosocial support.

Summary statements

All people living with kidney disease should have their psychosocial needs assessed using validated methods. This screening should take place at diagnosis, at changes in treatment, as they go through different stages of kidney disease, at times of distress and annually. This assessment should include the psychosocial needs of family members and carers.

All people living with kidney disease should have access to emotional, psychological and practical kidney-specific psychosocial support appropriate to their level of need: effectively providing a ‘stepped care’ model. This will require investment in additional support where there are currently gaps, and the provision of a range of support offers so that people can choose the options most relevant to them. Reliable information about the support that is available should be easily accessible through a range of trusted channels, for example the NHS website’s pages on chronic kidney disease.

Psychosocial support should be available to those experiencing lower levels of distress and need, and should not be dependent on a person meeting the threshold for a clinical diagnosis or qualifying for specialised social care. This will meet people’s needs proactively and pre-emptively as a way of preventing the escalation of distress.

All aspects of kidney care should be psychologically-informed, with all renal health care professionals recognising the importance of psychosocial care, and having the skills (through tailored training), the resources (including time), and the managerial support and supervision to be able to engage with the psychosocial needs of people living with kidney disease.

Psychosocial support for children and young people should be tailored to different development stages, and include a psychologically-informed transition from paediatric to adult care.

Groups at higher risk of kidney health care inequities should be identified so that gaps in provision can be filled. Co-design and coproduction, where support is designed and delivered in an equal partnership between professionals and people using services, will be necessary to ensure support offers are relevant, culturally-competent, age-appropriate, and easily accessible.

The quality of psychosocial support offered to people living with chronic kidney disease should be monitored routinely so that local services can assess how well they are meeting people's needs (including by a range of equality characteristics).

Further research into the provision of psychosocial support for people with kidney disease is under way. It is essential that as the evidence base emerges, it is utilised appropriately to inform the ongoing development of services, and that more research follows to ensure that we continue to learn what works and in what circumstances.

Recommendations

1. The NHS must invest in expanded and improved psychosocial support for people with chronic kidney disease (and other long-term conditions).
 - A. In England, this could be achieved through the next iteration of the NHS Long Term Plan or the Major Conditions Strategy.
 - B. In Scotland, the forthcoming strategy on Mental Health and Wellbeing should address the specific needs of people with long-term conditions, including chronic kidney disease.
 - C. In Wales, this could be included in an updated Together for Mental Health strategy, or a service specification on psychosocial support could be developed as part of the Quality Statement for Kidney Disease.
 - D. The delivery of the Northern Ireland Mental Health Strategy 2021-2031 should include psychosocial services for people with kidney disease, including children and young people.
2. Integrated Care Boards in England and Health Boards in Scotland and Wales should ensure that a stepped care model of psychosocial support is routinely available to everyone of all ages living with chronic kidney disease in their area.
3. Renal treatment service providers should ensure all of their staff are trained, supported and supervised to identify patients' psychosocial needs, to practice in psychologically-informed ways, and to offer low-level support and rapid onward referral where more intensive support is required.
4. Renal services should routinely assess the psychosocial health of their patients and ask regularly about the quality of psychosocial support they are offered.
5. Government should invest more funding into research in kidney disease and mental health to increase our understanding, and aid the ongoing development of services.

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