

Caring for people with kidney disease

Psychosocial health – a manifesto for action

National Psychosocial Working Group



the british
psychological society
promoting excellence in psychology



University of
Salford
MANCHESTER



Psychosocial – a definition

Throughout this document the term psychosocial is used to refer to the full range of psychological, psychiatric and social care needs.

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.



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Foreword

The National Psychosocial Working Group was established to bring together expert voices from across the specialist renal psychosocial care professions, alongside leading patient support charity Kidney Care UK, in one forum.

Research tells us that supporting the psychological needs of people with kidney disease helps them **live longer in much better health**, allowing them to enjoy time doing what they love with the people they care about. Yet, currently, most kidney patients aren't getting the psychosocial care they need.

Despite the Government's message of parity of esteem between physical and mental health, we still see wide variation in psychosocial care provision for kidney patients.

This manifesto, the product of extensive research in this field, lays out ten carefully considered recommendations aimed at achieving an integrated whole-system approach to the care a person living with kidney disease should receive.

The Group will work with health and care decision makers and commissioners to ensure all kidney patients have equity of access to the holistic care provision they need to live their lives well. It's not just a moral or ethical argument, with an ageing population and the increase in people living with multiple conditions, patients must be enabled and empowered to take control of their lives, and their healthcare. Good mental health and social provision has a significant impact, creating a greater focus on shared responsibility for health and reducing time spent in NHS care settings.

Social deprivation and increased risk of mental and emotional ill health associated with kidney disease are clearly linked, yet some hospitals still have no renal specialist, psychosocial provision for their kidney communities and a clear focus on the holistic needs of patients is not universally included in the provision of renal health care. As a result, symptoms of depression, anxiety and dementia are often undiagnosed and untreated. Loss of employment results in some kidney patients relying on food banks due to inadequate and inaccessible welfare support.

Evidence demonstrates that care delivered by a multi-professional team that includes renal psychosocial professionals leads to improved medical outcomes, timely commencement of dialysis with working vascular access and reduced mortality for people living with kidney disease.

At Kidney Care UK we support kidney patients right across the country every single day. We know their needs and we know the difference a comprehensive and integrated whole-system approach to psychosocial care provision would make for them.

I want us all to reach the point where we can truly say we are supporting patients to live well with kidney disease.



Paul Bristow, Chief Executive – Kidney Care UK
On behalf of the National Psychosocial Working Group

Summary of 10 recommendations

This report makes the following ten key recommendations for the improvement of the care provided for ALL people living with kidney disease.

When adopted, these recommendations will ensure that psychosocial needs receive the prominence they deserve in the care plans of all patients.

Identification of psychosocial care needs

- 1 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.

Provision of psychosocial care at all levels of need

- 2 All kidney patients to be provided with appropriate psychosocial input that fully supports their level of need, as part of their standard NHS care.
- 3 Psychosocial interventions should increase with a person's level of need.

Integration of kidney patient care

- 4 Psychosocial needs to be integrated into kidney patient care plans.
- 5 NHS Integrated Care Systems or NHS Health Boards to ensure different parts of the system are joined-up to support the psychosocial needs of people with kidney disease, as well as their physical health.
- 6 Multidisciplinary teams (MDTs) to integrate specialist renal psychology, counselling, social work and psychiatry to ensure kidney patients have access to all the support they need to help them manage their condition.

Psychosocial workforce needs

- 7 Staffing levels to be monitored to support access to psychosocial care.
- 8 All renal staff to receive training in the mental health needs of kidney patients. All mental health staff to have basic training on renal disease, causes and management.

Accountability and reporting

- 9 Minimum national standards of psychosocial care to be introduced and monitored so all patients receive equal access to the care they need, regardless of geography.
- 10 A dashboard to be created to monitor the success of psychosocial services in improving kidney patient health. National renal and mental health teams to determine number of people who are on both the renal and the severe mental illness registers.



In this manifesto, we set out in detail the case for change. But we cannot achieve this change alone; we need your help!

To find out how you can get involved and improve the lives of people living with kidney disease, please go to the 'How you can help' section.

Introduction

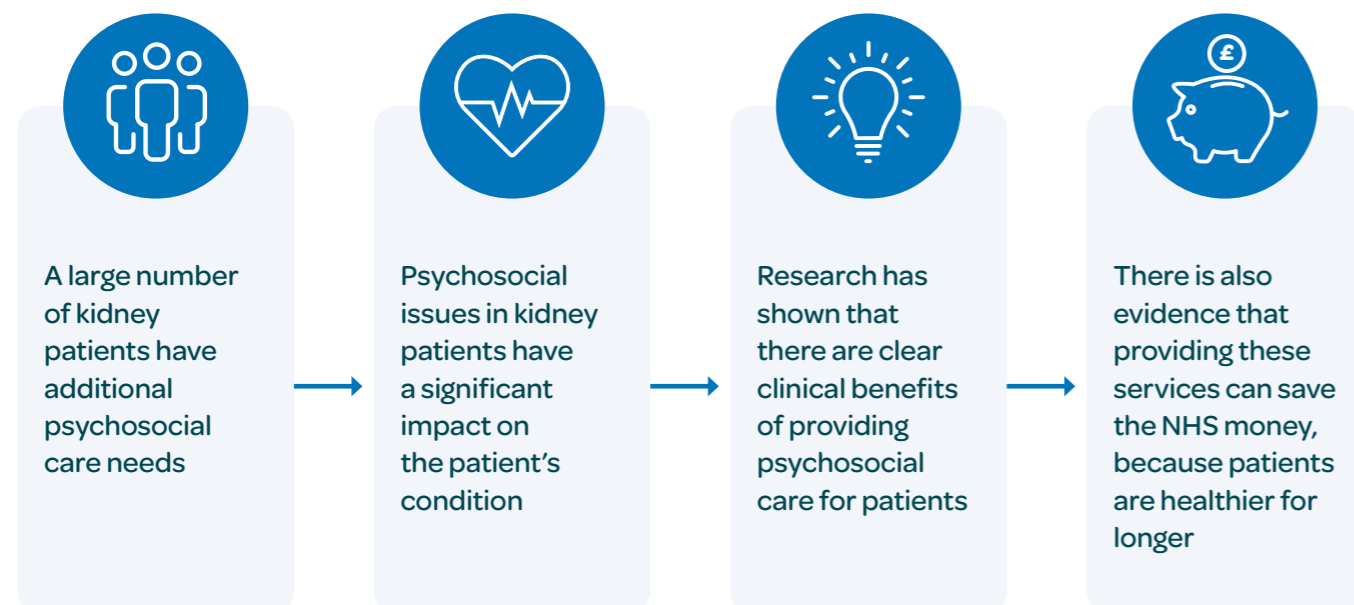


3 million people in the UK are living with chronic kidney disease¹

A chronic kidney disease diagnosis can have a huge impact on all aspects of a person's life, from their emotional wellbeing and mental health, to the ability to go about their daily lives without support from families, friends or carers. Psychosocial issues in kidney patients have a significant impact on the person's quality of life and can impact their physical health. There is therefore a clear and pressing need for psychosocial care, alongside the medical treatment kidney patients receive.



Why is psychosocial care so important to people with kidney disease?

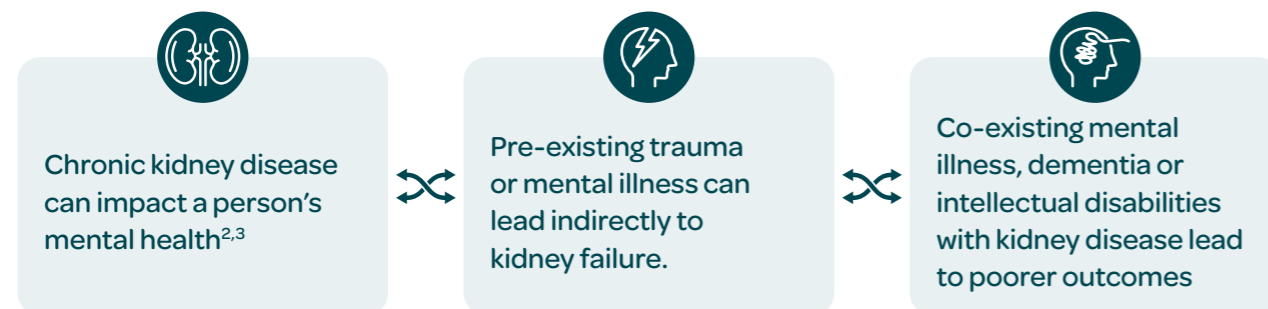


Psychosocial care saves lives! In this manifesto, we will describe the evidence on:



The relationship between mental illness and kidney disease and its impact

This is a three directional relationship.



1. Chronic kidney disease can impact a person's mental health^{2,3}

High burden and complexity due to:

- having to control what they eat and drink; taking numerous medications; and having very disruptive healthcare appointments e.g. multiple, long hospital appointments and frequent dialysis sessions.^{3,4}
- Nearly half of all dialysis patients experience some form of psychological distress.³
- The process of haemodialysis can itself, affect the memory and mental processes, for multiple and complex reasons including reduced blood to the brain during the session. There is increased likelihood of developing dementia on haemodialysis.^{4,5}

These factors can have a significant impact on kidney outcomes in the longer term, making the need for psychological and psychiatric care throughout their journey vital:

- Depression in early-stage kidney disease increases their risk of progressing to late-stage kidney disease, leading to the need for dialysis or a kidney transplant.^{7,8,9}
- Depression increases the risk of hospitalisation.^{10,11}
- Depression in people receiving dialysis and in kidney transplant patients increases the risk of dying by approximately 50% and 65% respectively.^{8,9,12}

2. Pre-existing trauma or mental illness can lead indirectly to kidney failure.

Adverse Childhood Experiences or ACEs, including emotional neglect, sexual abuse, and living with a caregiver with mental illness, have been linked to higher rates of developing kidney disease with higher rates of mortality than the general population.^{14,15}

Conditions like schizophrenia, bipolar affective disorder, dementia or intellectual disabilities can lead to increased chances of developing kidney disease and having poorer outcomes:

- The symptoms of different mental illnesses may affect the person's ability to self-care, understand or even believe the need for the treatment,¹⁶ e.g., someone with delusions may believe that they can cure themselves without medical intervention so refuse dialysis.
- Some psychiatric medications (antipsychotics for schizophrenia and Lithium for bipolar affective disorder) can lead to diabetes and/or kidney disease.¹⁷

3. Co-existing mental illness, dementia or intellectual disabilities with kidney disease lead to poorer outcomes

- People with severe mental illness (SMI) make up over 7% of all kidney disease patients but this is not fully quantified in UK.¹⁸
- People with SMI receive suboptimal kidney care, have fewer appointments with nephrologists, and are less likely to receive a kidney transplant.¹⁹
- People with an SMI have a life expectancy that is about 15 years less than the general population for multiple complex reasons which include reduced access to care and misdiagnosis.²⁰
- There are higher rates of dementia in people with kidney disease for many reasons, including the fact that both conditions have common risk factors like diabetes, high blood pressure and high cholesterol.²¹
- Dementia-like conditions are common in kidney patients but significantly under-diagnosed, leading to suboptimal care for both the dementia and the kidney disease.²² These conditions are likely to decline more quickly in dialysis patients and have a negative impact on their ability to make decisions about their treatment.²¹
- People with intellectual disabilities (or learning disabilities) and/or neurodevelopmental conditions are also at increased risk of advanced kidney disease.^{23,24}
- Neurodevelopmental deficits have been recognised as a major complication of paediatric kidney disease. Some of this impairment has been attributed to the possible effects of kidney failure: uraemia, anaemia, hypertension and malnutrition.²⁵
- People with intellectual disabilities are also at increased risk of mental illness. Studies suggest the rate of mental health problems in people with an intellectual disability is up to double that of the general population.²⁶



The patient voice



Nikki, kidney patient

“ I was 47 and exhausted physically and mentally. I'd needed two fistuloplasties on my ageing fistula. I'd been experiencing chest pain. I ached constantly. I'd stopped doing the things I enjoyed. One morning I couldn't face work... I was diagnosed with stress, anxiety and depression. Over the years I'd built this wall around me. I was untouchable, invincible. But I didn't recognise myself anymore. Nor did my home therapy nurse, who persuaded me to see the renal psychologist. What a godsend. Like a jigsaw, she emptied me, then gradually put me back together.

”

A liaison psychiatry consultant in a London hospital said:

“ Our renal dialysis nurses are so good at working with patients who may be distressed, confused or psychotic that we don't often hear from them in my team. But my whole team knows that if the dialysis nurses call you to say they are struggling to manage a patient, that patient is probably really quite unwell from a psychiatric point of view. Over the pandemic that burden of mental illness in our dialysis patients has increased and the impact on the welfare of both patients and the nurses has been tremendous. Having a psychiatric service has been a vital resource for the dialysis unit to ensure that patients keep having their dialysis.

”

Social care and kidney disease

Kidney disease can significantly impact the ability of people to go about their day-to-day lives without relying on families, friends or carers for support.

- Due to increasing frailty plus long hospital appointments multiple times a week, kidney patients may have to give up their jobs and claim benefits, potentially pushing them into poverty
- Around 25% of people with a mental health problem are in debt²⁷ and the overlap between financial issues and mental and physical health problems can cause vicious circles, in which financial problems negatively affect health.²⁸
- They may depend more on family members and carers or have caring responsibilities themselves
- Their housing may no longer be suitable and/or they may require home care

This means many kidney patients require social care services to meet their needs including at home support for domestic and personal care, support with taking medications and completing home treatments such as dialysis, accessible transport systems, welfare and housing support, help with renal diet and exercise regimes and more.²⁹ Receiving social care provision can improve kidney patients' mental health – patients in hospital kidney units with higher ratios of social care staff were less likely to experience distress.² This in turn improves the overall physical health.

However, over the past 15 years, adult renal social work resources have reduced dramatically, by nearly a fifth (19%), despite increasing numbers of patients. Despite the complementary nature of the different roles and responsibilities of psychology and social work services and clear evidence that psychosocial services should include both, the increase of the psychology workforce has appeared to come at a cost of the social work workforce.³⁰

There are also large inequalities in access to social care provision for kidney patients – nearly half (49.3%) of renal units have no adult renal social workers.

There is evidence that NHS policymakers and practitioners find it difficult to access good quality research and evidence to support social work interventions,³¹ – which could be impacting on social care provision.

Patient feedback:

“ Really helpful, to deal with anxiety and family politics following tx [Transplant] - allowed me to deal / process these, also address other stressors and my response as potentially my blood pressure could have been high. Had 6 or 12 sessions initially then weaned down to monthly - this worked very well, felt had safe place to go back to; flexibility of service really helpful and ability to be able to sign off and know I could go back

”

19%
decrease in
resources
since 2007

49%
have no access
to social
workers

Inadequate staffing levels across the units often mean Renal Social Workers are unable to attend Multi-Disciplinary Team meetings or visibly position themselves in the unit and that clinical staff lack the time to attend psychosocial training. This negatively affects the staff's ability to engage in negotiations to create a culture of psychosocial support in the unit and further exacerbates the lack of understanding about roles and responsibilities, which was found to be another factor for successful joint working.³²



A UK Renal Social Worker said:

“

The people we see on renal units have a wide variety of social care needs. For example, one of my patients was 22 when she crash-landed on to dialysis after a brutal assault by her ex-partner and several weeks in intensive care. She had a long history of drug abuse on the back of childhood sexual abuse, and had been diagnosed with a borderline personality disorder. She had been kicked out by her stepfather, so my first step was to find her appropriate housing.

”



A kidney patient perspective:

“

I feel useless. I can't clean, bake, I can't do anything as fast anymore. I wake up thinking it is a bad dream, but it isn't. My husband insists on doing the care, he doesn't want anybody else in the house. I am frustrated that I have to rely on people, I want to be able to get around independently, instead of my husband having to drive me everywhere.

”

What care should kidney patients be getting?

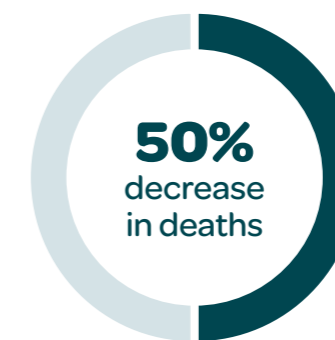
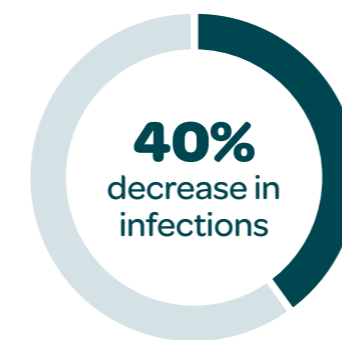
Supporting the psychosocial care needs of people with kidney disease helps them live longer in much better health, allowing them to enjoy time doing what they love with the people they care about.

Kidney patients are more likely to take their medication and look after their own needs if they have access to psychological support. Pre-transplant psychological preparation can also decrease the risk of non-adherence. This can increase the chance of a kidney transplant being a success.^{9,33,34,35}

Having psychosocial professionals as part of a kidney patient's treatment team leads to:

- 40% fewer patients needing to go to hospital due to infection³⁶
- Better prescribing decisions leading to patients' kidney function decreasing more slowly, delaying the need for dialysis and even reducing deaths from kidney disease by 50%³⁶

Kidney patients treated in units with higher numbers of psychosocial care professionals are less likely to experience distress, regardless of the person's age, ethnicity, time spent on dialysis, their living situation or employment status.^{2,37}



Patient feedback:

“

Counsellor helped me out of what seemed to be a very dark hole. I can't thank the counselling service enough and I would not be where I am physically or emotionally today, if it weren't for the service

”

Patient feedback:

“

It felt very holistic. My renal psychologist could relay medical information both general and that pertaining to myself to me, and discuss in a detailed way because of her psychological and renal training – she understood. And from both sides – medical, and psychological. I didn't have to start from a point of my psychologist being totally ignorant to the medical implications of my condition as a whole, and my individual circumstances – it was invaluable.

”

The patient voice

Jon Longhurst, kidney patient

“

I am a type 1 diabetic of 35 years and was diagnosed with end stage kidney failure. Despite my diabetes, I have had an extreme needle phobia since very early childhood.

Counselling has helped me undergo a number of invasive procedures over the past year, all of which were a requirement for me to be accepted onto the SPK (kidney and pancreas) waiting list. This amounted to both counselling and a pronounced degree of advocacy by my counsellor, enabling me to meet with the practitioners involved and voice my particular concerns with them.

Without this, I am certain that I would not have agreed to any of the procedures and hence would have been barred from the waiting list.

Things came to a head when my kidney function dropped below 5% and I collapsed in hospital and was admitted into the renal ward. I was vomiting continuously, was severely dehydrated and was told I would die without dialysis and even if I got called for the transplant, I would not be fit enough to survive it. I was discharged and returned home still steadfast in my belief that I would not and could not endure dialysis. The first thing the next morning I phoned my counsellor before she was even in the office and, thanks to her extensive medical experience, she patiently explained the procedure in a pragmatic way and knew what could realistically be done to make things easier for me. Throughout the course of the day, she liaised with the doctors and was able to get them to agree to anaesthetise me with gas to put a tunnelled line into my neck for dialysis, which I was willing to accept if it were done in this manner. This avoided the need for any cannulas, which I refuse to suffer. I spent over 4.5 years on haemodialysis and have subsequently undergone major cardiac surgery prior to receiving my kidney and pancreas transplant.

Given my very strongly held views and the often, inflexible attitude of many doctors I have encountered, I do not think it any exaggeration to say that my counsellor's support and advocacy on my behalf during this summer saved my life. Without it I would not have agreed to dialysis and so would not have survived.

”



Why now?

Kidney Care UK as well as our colleagues in the National Psychosocial Working Group have been calling for increased care for patients for years. It is needed now more than ever!

1
NHS resources are stretched but the need for psychosocial care provision for kidney patients is growing³⁰

3
Covid-19 impact

The COVID-19 pandemic has had a huge impact on people with kidney disease. Around 70,000 people with kidney disease are deemed clinically extremely vulnerable to COVID-19 and were advised to shield from the outside world for months on end. Yet those needing dialysis had no choice but to make the terrifying trip into hospital 3 times a week to receive their treatment.

A survey of more than 1,200 kidney patients by Kidney Care UK during the first wave found that more than 4 in 10 people felt their mental health had been affected.⁴⁰

4
Pre-existing inequalities

Whilst Covid has highlighted these issues very clearly, it must be noted that lack of social and mental health care, and a high need for it, was already a feature in kidney care, and will still be there after the pandemic.

2
Improved psychosocial care provision in kidney services will also address challenges important to the wider NHS:

- **Health inequalities.** Understanding and supporting the psychosocial needs of patients in relation to their own cultural or socioeconomic background is crucial to improving health inequalities.
- **Prevention of ill health.** Psychosocial care assessments and interventions help prevent the worsening of symptoms and of overall health – including helping patients take their medication correctly and improving self-care.³⁶ Lending support to the vital role of specialist psychosocial interventions was a Health Foundation report published in August 2018.³⁸ This report highlighted that patients who were most able to manage a mental health condition, as well as their physical health conditions:
 - experienced 49% fewer emergency admissions than those who were least able.
 - had a length of stay in hospital 41% shorter compared to those least able
 - 32% fewer A & E attendances
 - 18% fewer GP appointments
- **Cost Effectiveness.** The experience of CKD and its longer term physical and psychological consequences can also have a significant economic cost. Healthcare costs for people with long-term conditions are 50% higher in people with depression and/or anxiety disorders (36). Psychological therapy reduces physical healthcare costs by an average of 20% (meta-analysis of 91 studies). When data is available on cost of psychological treatment and physical healthcare, savings exceeds costs.³⁹

10 Recommendations for change

People with kidney disease deserve to live longer lives in the best possible mental and physical health

Identification of psychosocial care needs

1 Every kidney patient should have their psychosocial care needs assessed using validated methods:

- at point of diagnosis
- as they transition or change treatment
- as they progress through the different stages of CKD
- at times of distress
- annual screening

Assessment should be conducted by renal specialist, co-located professionals in psychology, psychiatry and social care.

This should cover psychosocial distress and cognitive impairment (dementia). Routine distress and cognitive screening assessment should be provided to identify those who need additional support. Easily adopted, short screening tools are available for this.

Provision of psychosocial care at all levels of need

2 Every kidney patient should be provided with appropriate psychosocial care that fully supports their level of need, as part of their standard NHS care.

NHS leaders should make sure that these services are provided for ALL kidney patients

3 Psychosocial care interventions should increase with a person's level of need.

A traffic light system should be considered, where the level of a patient's psychosocial care need is standardised, and levels of care increase in intensity along with a person's needs. For example, patients could be referred to Improving Access to Psychological Therapies (IAPT) community for general counselling if the individual's disease is not currently getting worse or they don't yet require dialysis, transplantation or end of life care. Particular groups of patients should be offered enhanced or specialised renal specialist psychosocial care.

Integration of kidney patient care

4 Psychosocial care needs should be integrated into kidney patient care plans (which are produced by a patient's hospital kidney team).

These plans should contain easily accessible information about their condition, what to expect from their diagnosis, symptoms to look out for and how they can access interventions and support. Kidney teams should co-produce care plans with mental health teams of people with severe mental illness, dementia or learning disability.

They should include signposting to external resources relevant to their local community or cultural and ethnic backgrounds.

There should be outreach to at-risk groups, particularly those from different ethnic, cultural and socioeconomic backgrounds to understand more about their specific needs.

5 New NHS Integrated Care Systems should ensure different parts of the system are better joined-up to support the psychosocial care needs of people with kidney disease, as well as their physical health.

We want to see improved links between renal specialist psychosocial services and NHS Improving Access to Psychological Therapies (IAPT) services, secondary mental health and social care services, primary care and the third sector.

6 Renal multidisciplinary teams (MDTs) should integrate renal specialist psychology, counselling, social work and psychiatry to ensure kidney patients have access to all of the support they need to help them manage their condition and the complex interactions between mental and physical health.

In other diseases areas, such as diabetes, cancer and cystic fibrosis, MDT clinics hold annual reviews where physical and psychosocial issues are considered jointly.⁴¹⁻⁴⁷

Psychosocial care workforce needs

7 Staffing levels should be monitored to support access and equality to psychosocial care.⁴⁸

8 All renal staff should receive training in the mental health needs of patients so that they are able to act as "first responders" and know who and where to refer patients. Mental health staff should receive training about renal disease screening and management for their patients with severe mental illness and dementia.

In cancer and diabetes services, specialist nurses are trained to provide lower-level psychosocial provision with specialist supervision. Many nationally accredited diabetes training programmes have psychosocial modules embedded.

9 **Minimum national standards of psychosocial care should be introduced and monitored so all patients receive equal access to the care they need, no matter where they are in the country.**

Nationally there is significant variation in access to integrated psychosocial care.

NHS national service specifications and commissioning guidance should be updated to include integrated psychosocial care provision, along with physical health.

10 **A dashboard should be created to monitor the success of psychosocial care services in improving kidney patient health.**

This is available in other parts of the NHS, for example, the Diabetes Transformation Programme in North West London has mental health screening on its dashboard.

National renal and mental health teams should gather data on how many people are on both the renal and the severe mental illness registers.



How you can help achieve change

Our 10 recommendations are specific and patient-centred. Action is needed if we are to achieve a comprehensive and integrated whole-system approach to psychosocial care provision.

What we are doing:

- We will continue to operate as a National Group, ensuring a single unified psychosocial voice to provide support and oversight, holding Commissioners and Hospitals to account.
- We will widely circulate this manifesto and its 10 recommendations, for both awareness and action, to Health Ministers, Departments of Health, Parliamentary Health Committees, individual politicians and others in a position to influence change at all levels of Government in all regions of the United Kingdom.
- We will work with the National Renal Services Transformation Programme and other key bodies to seek consensus on these standards and work to ensure they are incorporated in the Renal Service Specification and monitored via publicly available Dashboards.
- We will engage with and support renal clinical directors and senior decision makers to review their patient pathways and workforce plans to identify gaps and ensure provision is put in place that meets stated Manifesto standards.
- We will harness the voice of the patient and carer community to ensure their voices are heard and are at the centre of informing and delivering change.

What you can do:

NHS leaders, ICSs & Policymakers

- Make parity of esteem between mental and physical health a reality for kidney patients
- Commission services that fully comply with the 10 recommendations in this manifesto
- Ensure that specific renal psychosocial support is commissioned, monitored and reported back through publicly available dashboards
- Acknowledge the benefit of psychosocial care provision for kidney patients

Clinicians

- Review your Patient Pathways and workforce plans to identify gaps in current provision against the 10 manifesto recommendations and implement improvements.
- Listen to your patients to identify their needs and demand further resources.
- Engage with local commissioners and help us make the case for improved access to psychiatric, psychological and social support for kidney patients

Patients and Carers

We want to hear your stories. Get in contact with us and share your experiences, both good and bad, so we can ensure that patient views are placed at the heart of the debate around getting these recommendations put into place.

If you are concerned about the level of psychosocial support you, or the person you provide care for, are receiving please make the health professionals who are responsible aware of this manifesto, and specifically the ten recommendations.

Tell us your experience via policy@kidneycareuk.org



To view the latest updates, scan the QR code or go to www.kidneycareuk.org/psychosocial-health-manifesto

Kidney Care UK patient support

We are the UK's leading kidney patient support charity, providing practical, financial and emotional support for kidney patients and their families and campaigning to improve care services across the UK.



Scan to find out more about our work or go to www.kidneycareuk.org/about-us/our-work



We are the leading UK provider of grants to kidney patients. Our trained Advocacy Officers are ready to help with local issues around treatment choice, patient transport and benefit concerns.



We will continue to provide seed funding to NHS Trusts who want to work with us and share our vision to provide patient-centred services where none exists.



Our counselling support team offers free telephone counselling to support where statutory services don't exist or where patients would rather talk to a Charity.



We provide grants for those unable to fund a holiday or short break away from the monotony of kidney disease, as well as supporting Dialysis Swap - a UK scheme to help patients find dialysis away from base.



Our hospital grants fund essential psychosocial staff as well as improving facilities and care.



We work at a national and government level to improve health and care services for kidney patients. Everything we do is about ensuring that the patient voice is at the heart of national decision-making. We have a Patient Advisory Group which actively supports us in all our work.



We will continue to support the renal psychology, counselling and social work associations to ensure they are able to have a strong united voice.



Meet the team

About the National Psychosocial Working Group

The group was set up by Kidney Care UK in 2020 to:

- raise the profile of the critical role of psychosocial care for kidney patients
- improve equal access to the highest quality, timely and renal specialist psychosocial care for all
- ensure psychosocial care assessment is a routine part of care and is provided by hospitals and other NHS providers
- improve awareness, diagnosis and management of psychosocial care needs of kidney patients



Amanda Bevin,
Co-Chair Renal Psychological Therapists (RPT)

I am a UKCP Registered Psychotherapist, qualified EMDR therapist & Supervisor. I have worked for the Kent Kidney Care Unit in Canterbury, Kent as the lead Specialist Renal Counsellor since 2007. I came to the UK in 1991 from New Zealand to travel. But ended up working in the NHS as a Registered Mental and General Nurse. I have worked in renal since 1992, and latterly in the NHS as a Counsellor since 1999. I am the co-chair of RPT (Renal Psychological Therapists) group since 2020, having previously chaired 2012-Nov 2020.



Paul Bristow,
Chief Executive, Kidney Care UK

Following a successful career in Senior Marketing and Communication roles in the private sector, including a FTSE 100 company, Paul has spent over 10 years working in national charities with a particular focus on long term health conditions, disability and disadvantage, as well as mental health. These roles have included Director of Marketing and Communications at Shaw Trust as well as Marketing and Corporate Communications Director at the Mental Health Foundation.

Paul has been at Kidney Care UK since 2014, where he joined as a member of the Senior Management Team to head up and develop the marketing and communications function as well as the development and promotion of a range of new patient support services to ensure that the patient voice is at the heart of improvements in health and care services in the UK. Paul was appointed Chief Executive in May 2020, after previously holding the roles of Deputy and then Interim Chief Executive.



Emma Coyne,
Chair of Renal Psychologists Network, British Psychological Society

Emma is a Consultant Clinical Psychologist and is registered as a Practitioner Psychologist with the Health and Care Professions Council (HCPC). She leads the Renal Psychology Service in Nottingham. She has worked in renal since 2009, having previously worked in adult mental health services, paediatric diabetes and pain management.

Emma is the Chair of the British Psychological Society: Renal Psychology Network. She regularly lectures on local Clinical Psychology Doctorate courses and contributes to nurse and medical education courses locally and nationally.

In addition to her clinical work, Emma has carried out research in a renal setting in a number of areas including young adult care, staff wellbeing, and being a parent on dialysis. She is currently involved in a project to develop psychological interventions tailored for renal patients.



Margaret Eyre,
UK Renal Social Work Group

Worked in frontline services since qualifying as a social worker in 1986.

Member of hospital discharge team for nearly 20 years and renal social worker since 2012; previously employed for seven years as a social worker with visually impaired people.

RSW Group rep on BRS Council, contributor to workforce planning document. Practice educator since 1991, supervising over 30 students; additional freelance work for York University facilitating groups for students on placement.

Qualified as Best Interests (Deprivation of Liberty Safeguards) Assessor in 2009; due to transfer to work as an Approved Mental Capacity Professional under the new Liberty Protection Safeguards.

Member of hospital discharge weekend social work team; previously worked as part of multi-disciplinary team in A&E designed to prevent hospital admission.



Fiona Loud,
Policy Director, Kidney Care UK

Fiona is Policy Director of Kidney Care UK, working with policymakers and others in campaigning for the organ donation opt-out law, improving access to transplantation and patient choice. Previously Director of the Kidney Alliance, she co-authored the review of kidney care, Kidney Health: Delivering Excellence. She works with many groups to improve care standards for kidney patients, such as dialysis choice or patient transport. She set up and chaired the UK Renal Registry patient council and been a member of many NICE kidney guideline groups. She is lay chair of Watford hospital organ donation committee and vice chair of her local kidney patient association at the Lister hospital.

Fiona spent 5 years on dialysis after her kidneys failed, before a transplant from her husband in 2006. She is a Fellow of the British Renal Society and was one of the Health Service Journal Top 50 patient leaders.



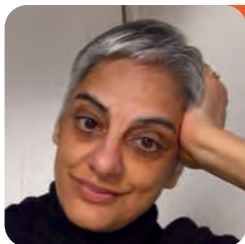
Professor Paula Ormandy,
Long Term Conditions Research, Salford University

Paula Ormandy is a Professor in Long Term Conditions Research, University of Salford. Originally a renal nurse she has built a career in health service research spanning 30 years. Research interests include patient experience, self-management education, and information to meet the psychosocial needs of people managing multiple long-term conditions, using digital/social media. She worked with the British Renal Society, as Vice President Research, Chair of the Research Committee, and first non-medical Chair of the UK Kidney Research Consortium. Now Executive Director and treasurer for the Association of Nephrology Nurses (ANN UK). Founding member of Kidney Information Network using digital/social media to inform and connect kidney patients with their peers for support. Co-chair of Kidney Patient Involvement Network working to increase kidney patient involvement in quality improvement, research, and service design.



Dr Joseph Chilcot,
Reader in Health Psychology, King's College London

Dr Joseph Chilcot is a Reader in Health Psychology and Head of the Health Psychology Section, at the Institute of Psychiatry, Psychology & Neuroscience, King's College London. His research is focused on the psychological aspects associated with long-term conditions, particularly advanced kidney disease. Joe is interested in the role cognitive and behavioural factors have upon symptoms and their trajectories (including distress and fatigue) and how these relate to clinical outcomes. He is also interested in the detection, management and treatment of depression among individuals living with kidney disease and other LTCs.



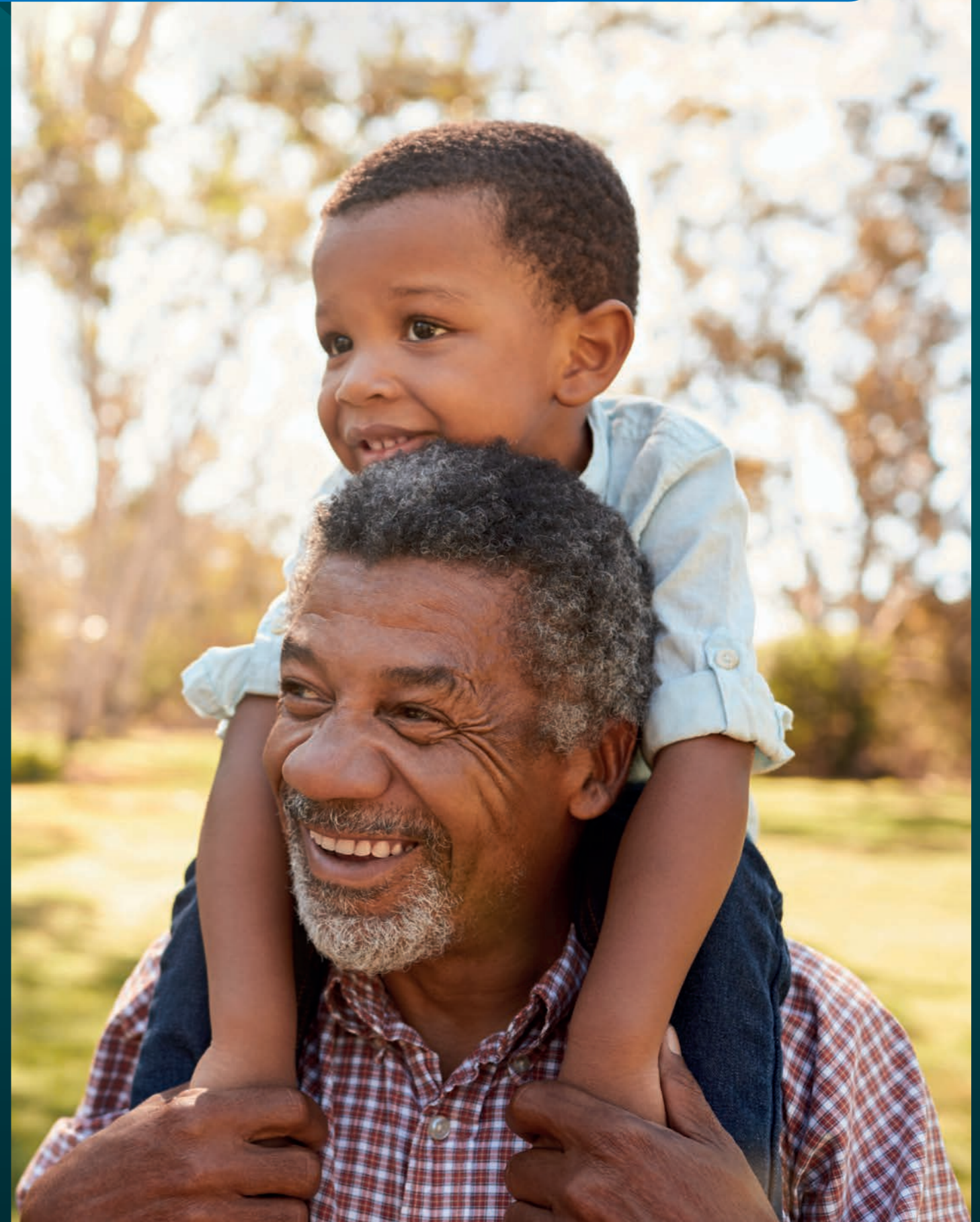
Dr Amrit Sachar,
Faculty of Liaison Psychiatry, Royal College of Psychiatrists

Amrit is a liaison psychiatry consultant in Imperial College Health Care NHS Trust and West London Mental Health Trust and a Health Foundation Generation Q Fellow having completed a Masters in Leadership of Quality Improvement.

Her clinical and strategic work has centred around the mental health aspects of diabetes, renal disease and other long term conditions, working with Diabetes UK, Kidney Care UK and NHS England to recommend system level changes.

Her other areas of interest are Organisational Development, health and workforce inequalities and she is currently a Royal College of Psychiatrists Equality Champion working nationally on the workforce equality.

Thank you for supporting people living with kidney disease!



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Kidney Care UK, 3-4 The Windmills,
St Mary's Close, Alton, GU34 1EF

01420 541 424

www.kidneycareuk.org

Fiona.loud@kidneycareuk.org

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