

THE RAM PAGE

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QUALITY OF LIFE SURVEY– *What it means for you?*

Over the past few months some of you may have received a Quality of Life Survey and wondered **what its' end use was to be.** This survey has been developed to give an objective measurement of how kidney disease is impacting on various areas of your life. It may be used to holistically meet the needs of patients or for other purposes such as informing changes to the Renal Service over time .

The Kidney Disease and Quality of Life questionnaire (KDOOL for short) is written as a self – administered survey and has been endorsed by the Survey Resource group (who endorse all surveys used within the hospital). The data is collected from different consumer groups within the Renal Service at regular intervals over the year. The results are collected from individual renal patients in a way that does not identify them and then scored to produce health profile scores for areas such as physical, social, emotional and mental functioning, bodily pain, general health, vitality, symptoms, burden of illness, staff encouragement, and patient satisfaction.

It is a way of screening for poor Quality of Life and targeting interventions to help. The results are particularly useful for doctors seeking to understand which areas of patient health are most compromised. The survey may also be used to work out how the Renal Service is doing at treating renal patients generally, and to help the service to improve its' care.



Caring for carers



When her daughter's condition got worse, Jane's caring role became much tougher and she knew she needed some help. But her attempts to navigate the system more often than not ended in confusion, frustration and even greater stress. Eventually, Jane called Carers ACT and soon after her situation improved dramatically.

Carers ACT provided Jane with counselling and short-term respite and guided her family to a range of other services that have made life at home much easier.

In her words, "All of a sudden, there was light at the end of the tunnel. I wish I had called Carers ACT earlier."

If you look after a family member or friend who has a chronic illness and you need some assistance, contact Carers ACT today. We will help you find the way.

Recognising yourself as a **'Carer'** is the very first step to getting the help and support you need.

Looking after someone in your family with a chronic illness adds an extra dimension to your role as parent, spouse, child, sibling or neighbour. Every care situation is different. Some people who are fairly independent may need help with tasks such as banking, transport, shopping and housework.

Carers help their family members to have a good quality of life.

While caring is part of loving someone close to you, it can take its toll on your own health and wellbeing. This can subsequently impact on the person you are caring for. Carers ACT can support you to get the help you need, when you

need it. Over 2.6 million Australians provide help and support to a family member or friend - caring can happen to anyone, anytime.

Information About Services in your Community

If you live in the ACT or surrounding region and need to know about services in your local community, eligibility and costs - you need only call the Commonwealth Respite and Carelink Centre on 1800 052 222.

The Carer Advisory & Counselling Service
Ph: 1800 242 636

If you are a carer and live in the ACT or surrounding region you can make just one call to 1800 242 636 and you will be linked into supports and services for carers. We can help you understand the service systems, access information about the health condition of the person you are

caring for, financial assistance, how to maintain your own health and wellbeing or money and legal issues. We can support your emotional needs by organising counselling appointments or link you to specialist support groups in your nearest community. This service is offered to carers living in the ACT by Carers ACT

and in NSW by Carers NSW.

If you are from a non-English speaking background, think about joining one of our many ethnic support groups. The groups are facilitated by a Bilingual Group Leader and offer practical information on issues of interest to Carers and can link you to services and ongoing support. Interpreter services are available on request.

Respite – 24/7 – 1800 052 222

Taking time out to relax can be good for both you and the person you are caring for. There are many different types of respite support available. We





aim to be as flexible as possible to best meet your needs including the provision of direct and indirect respite.

Advocacy and Speaking Up

An advocate is someone who will speak up for you, or help you to speak up for yourself, so that your views are heard and taken into account.

Caring becomes easier when the people and organisations that support you understand your needs and the needs of the person you care for. The Carer Advocacy Service can help you understand your rights and entitlements and how to negotiate services.

Education Information Sessions & Social Events

Carers ACT's many information enable you to develop strategies and skills that could help you manage your caring role while maintaining your own wellbeing. Check our website or newsletter for upcoming workshops.

Meeting other Carers can give you peace of mind that you are not alone and provides opportunities to make new friends. Carers ACT hosts



regular social events such as private viewings at the National Gallery of Australia, outings and day tours. The *Carers Hub* is available for you to meet up with other Carers over a coffee,

borrow one of our many books and DVDs and access the internet.

Have Your Say

Carers ACT is the recognised representative voice of family Carers across the ACT and our mission is to lead change and action with and for Carers. We actively engage with around 7,000 caring families in the ACT and are committed to ensuring that the views of Carers are included when government policy and service delivery systems are planned and evaluated. We work closely with Carers Australia and the Network of Carers Associations on issues of Territory and national significance for Carers. If you would like to be involved in working with us on our campaign for change for Carers, give us a call today on: (02) 6296 9900.

Carers ACT can also assist you to access respite services and support through the Commonwealth Respite and Carelink Centres (CRCC) covering the ACT and South Eastern Regional NSW. Please call: 1800 052 222 for assistance.

Contact

Carers ACT

Ph: (02) 6296 9900

Joke of the month

Two men were talking about their problems while waiting to see the nephrologist. One said to the other, "Just when we learn to take things with a grain of salt, the doctor puts us on a salt-free diet!"

Email: Carers@carersact.asn.au

INTRODUCING YOUR CONSUMER REPRESENTATIVES

They Represent You on the Renal Advisory Meeting



CO-CHAIR

JOHN SCOTT : 6255 1320

CARERS ON THE RAM AND ALSO THE

CANBERRA REGION KIDNEY SUPPORT GROUP

JOHN KELLY-EMAIL : CARERS@CRKSG.ORG.AU.

"I am the carer of a renal transplant recipient. I am more than happy for people to contact me. Phone : 02 6231 4286. If I am not there please leave a message on how to contact you."

"I am a Renal Transplant patient who has had Kidney disease since 1973. My kidney's finally failed in 1988. Over the years I have had Haemodialysis treatment both in-centre and at home as a home dialysis patient. I have been on the Renal Advisory Meeting from the beginning and am a former Senior Public Servant in the Commonwealth Health Department. I work privately in the area of risk identification and management"

CANBERRA COMMUNITY
DIALYSIS CENTRE

LOUISE BLUE : 0438 116 818

"I have been on dialysis for nearly 4 years. I am happy to talk to people either by phone or directly over coffee etc. Please feel free to contact me or leave a message and I will get back to you"

HOME HAEMODIALYSIS

NICK CLARKE- EMAIL : NICLIN@PACIFIC.NET.AU

"Happy for anyone to contact me on 0419 605 435 or at the above email. I have been on dialysis for nearly 8 years and nearly 6 of that has been at home (nocturnal)"

TRANSPLANTATION AND ACUTE
HAEMODIALYSIS

JENNY WATSON : 0431 099 394.

"I have been a dialysis patient and a kidney recipient and I would be willing to talk to anyone if they want to contact me on the above phone number."

YOU CAN BE ONE OF THE REP'S TOO

The renal advisory meeting objectives are to provide a forum where mutual information, advice and assistance can be provided to both the staff and patients at the renal unit at the TCH that relate to issues that may arise that may assist with:

- ◆ understanding the needs of all stakeholders in the renal services
- ◆ identifying initiatives that may improve patient care and well being
- ◆ provide a forum where open communication can be established and distributed through various networks
- ◆ improve the services that are provided by ensuring that they are consumer driven and focused on improving outcomes.

We currently need consumer representatives from CCDC, Northside, 8A, PD and Home Therapies.

Generally there is one meeting each month, held in the Renal Administration area and takes about 1 hour of your time.

If you would like to become involved please contact this office and further information will be provided.

Email: shradha.waddepalli@act.gov.au