

THE RAM PAGE

-MAY 2015-



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Apple & Rhubarb Crumble

Serves 6

Ingredients:

425g canned pie apple
2 cups chopped rhubarb
2 tablespoons sugar
2 tablespoons water
2 tablespoons honey
2 teaspoons margarine
1½ cups cornflakes
½ cup plain flour

Low fat vanilla ice cream - 6 small scoops (25g each)

Method: 1. Preheat oven to 180 degrees Celsius
2. Place rhubarb, sugar and water in a saucepan, cover and cook for 8-10 minutes until rhubarb is soft. Stir in pie apple and mix well.
3. Spoon fruit into a greased ovenproof dish.
4. Combine honey and margarine in a small bowl and microwave on high for 20 seconds.
5. In a separate bowl, combine cornflakes and flour. Stir in honey mixture. Spread over fruit and bake for 20-30 minutes until golden. Serve hot with a small scoop of vanilla ice cream.

This recipe is suitable for people on:

Peritoneal Dialysis Haemodialysis

Each serve of this recipe will provide:

Apple & Rhubarb Crumble

750kJ, 3g protein, 1.3g fat, 37g carbohydrate, 160g potassium, 40g phosphate and 96g sodium

Apple & Rhubarb Crumble with 1 small scoop (25g) low fat vanilla ice cream

865kJ, 4g protein, 2g fat, 42g carbohydrate, 210mg potassium, 80mg phosphate and 100mg sodium



Vale “Our Dear Jenny” – A Life of Giving

30th April 1950 – 30th October 2014

Jenny Watson was an incredibly strong woman who spent a life of giving to others around her. But her life was not an easy one.

Having emigrated from England, the hardworking Jenny brought up 4 gorgeous children for the most part as a single ‘fun mum’ – a description her children gave her.



Jenny ‘overcame’ cervical cancer in 1989 however shortly after moving to Queensland in 2005, Jenny’s kidneys failed. This meant undergoing a 3 – 4 hour haemodialysis treatment 3 times a week for the next 4 years. While this was a very hard time in her life, Jenny remained positive and never complained.

In 2009 Jenny was offered a kidney transplant. This was an amazing gift and gave Jenny another chance at a fuller life. This also allowed Jenny to meet 3 more of her 6 grandchildren, watch one of her daughters walk down the aisle and visit England with another daughter and partner for the first time in 40 years.

Life was full ... however, there was always space in Jenny’s large heart for others.

Jenny was invited to become a consumer member of the Renal Advisory Meeting (affectionately called “the RAM”). At these monthly meetings, Jenny and other consumer representatives actively work with Renal Specialists, renal nurses and allied health professionals to improve the ‘experience’ of people with kidney disease and their carers. The “RAM” continues to today and provides an important avenue for patients and carer ‘voices’ to be heard.

Having a sense that both renal patients and their carers might benefit from having a relaxed environment where they could share, support and learn from one another, Jenny established a Monthly Morning tea. This has been running for about 4 years now and is currently held at the Hellenic Club at Woden. The Morning tea has been a great success and is a legacy to Jenny’s contribution in providing a ‘safe’, friendly and inclusive environment for prospective, new and longstanding patients with renal failure and their families.

Jenny was also a great teacher and loved to share her knowledge, skills and lived experience to assist others. So, when approached to be a co-leader to conduct the Stanford University based course “Living a Healthy Life with Chronic Conditions,” Jenny jumped at the opportunity! After a rigorous formal education, mentoring and evaluation program, Jenny co-lead three of these six week courses over a 2 year period. True to form, after each session, you would often find Jenny in deep conversation with one of the participants. There was no end to her giving!

As part of her giving spirit, Jenny also formally offered her skills and time as a volunteer at the dialysis unit at the Queanbeyan Hospital. She was the first. In spite of now needing to use a walker, every week, Jenny would take the bus to Queanbeyan Dialysis Unit where she made up the individual “run on packs” for nurses to use when connecting patients to their dialysis machines. This saved the Unit money but more importantly was something that Jenny could do sitting down, and provided her with the opportunity to talk to the patients and their families. She was ‘part of the family’ helping distribute morning teas and entertaining everyone with the latest news or photo of one of her beloved children or grandchildren. A memorative plaque will be placed at the Unit this year ... for “Our Dear Jenny” who is greatly missed.

Further Information

If you or someone you know would like to learn more about the supports available for people and their families with kidney failure, or are interested in sharing their knowledge, skills and experiences living with renal failure, please feel free to contact the Chronic Kidney Disease Nurse on (02) 6174 5090.

*** Acknowledgements**

Many thanks to Jenny’s family for allowing us to use some of the words from her eulogy to describe Jenny’s life. Thanks also to the many clinicians who shared their lovely stories of “Our Dear Jenny”.

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Written by Joan C Scott and first published in the Queanbeyan Age on Friday 10 April 2015

Visits to regional areas of the Renal Service Network

My wife Joan and I have had the privilege of visiting the patients, carers and staff of the NSW Renal Dialysis units of the Renal Service Network located in Moruya, Queanbeyan, Bega and Cooma with a Goulburn visit scheduled for June.

I felt it was important for me, as the Patient Co-Chair of the Renal Advisory Meeting (RAM) to visit each dialysis centre to better appreciate the issues affecting renal patients, carers and staff in each regional setting. This experience built on the 2010 "Open Space" conversation in the ACT where we discussed "How to make the Renal Dialysis Experience better".

Our visits were not intended to be formal or extensive. Rather, each visit simply provided an opportunity to meet some patients and carers as well as local staff to hear what they wanted to share. Our visits were deliberately low-key events. We were welcomed by all and treated with hospitality—something Joan and I very much appreciated.

So what did we learn?

We were struck by and reminded of the strong sense of local community and the resilience of the people and communities of regional areas; this is something which you don't see in bigger cities like Canberra.

We gained a better and more 'up close and personal' sense of the real issues---like not having enough dialysis chairs in the local communities to meet their needs.

We got the impression that while transport to dialysis and renal clinic appointments was still an issue, the cost in terms of travel and time had improved since the establishment of regular regional clinics run by ACT-based Renal Specialists. It will be further improved with the opening of additional dialysis chairs from funding provided by NSW Health.

We appreciated the tremendous amount of effort (above and beyond) put in by doctors, nurses and administrative staff to work out how to work better together to improve the delivery of care for of all patients and their carers within the Renal Service Network.

We were also conscious of the hope to realise the significant benefits that the planned establishment of the cross-border electronic connection will bring in enabling treating team members to share accurate and timely clinical information seamlessly across geographical boundaries. The results of this work are already apparent across the ACT.

In short, we were pleased to see the firm foundations of the Renal Service Network from the very visible commitment of everyone to work together to provide safe, high quality and efficient care to renal patients and their carers. We were also humbled and proud to be able to be a small part of and share the journey over the last few years in improving the quality of care and experience of renal patients and their carers.

John Scott

Patient Co-Chair, Renal Advisory Meeting

MORNING TEAS 2015 DATES REMINDER ~

VENUE: HELLENIC CLUB COFFEE SHOP, MATILDA ST, WODEN

WEDNESDAY, 17 JUNE, THURSDAY, 16 JULY,
WEDNESDAY, 12 AUG, THURSDAY, 17 SEPT,
WEDNESDAY, 14 OCT, THURSDAY, 12 NOV,
WEDNESDAY, 16 DECEMBER

ANY ENQUIRES PLEASE CONTACT, JOHN KELLY ON
0450 962 155

~ Nutrition Reminder ~

Your diet plays an important role in managing all stages of your Kidney Disease. It is important to see a specialist **Renal Dietitian** for regular follow up appointments.

To see a Renal Dietitian please ask your nephrologist or dialysis nursing staff for a referral or phone the Canberra Hospital Nutrition Department on **6244 2211**.

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 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"

"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."

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"

GENERAL TEAM PASTORAL CARE

MARY CORCKERON : 0427473290

While clients receive professional care from nursing staff and those involved in their care from other disciplines, Spiritual Care is an essential aspect of caring for the whole person. I am a friend and spiritual companion which when summed up translates as one who LISTENS.

BARRY COLE: 6288 2036

I was a full time carer for about 10 to 12 years for my late wife. For the last 6 yrs of her life she was a PD patient. For the remainder of her life (July 2014) I used to set up the unit for night time use then clean out and empty out in the mornings 7 days a week. I am also part of the "Aspree" research group for older persons.

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 **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