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To The General Manager,

**Re: SVC Draft Home Dialysis Rebate Policy feedback**

Thankyou for the opportunity to provide feedback on the above draft policy.

I note that the proposed SVC Home Dialysis rebate is for 120kl per annum, which is significantly less than the Dialysis Rebate offered by the former Tumbarumba Shire for patients like myself, or offered by other jurisdictions.

The former Tumbarumba Shire Council policy was to supply, at no cost, the water used in the dialysis machine, providing a statutory declaration is received stating the annual water consumption of the home dialysis equipment.

This policy meant that council only subsidised the volume of water used for individual treatment, despite differences in prescribed regime.

As published in the KHA Home Dialysis rebate guide, the average Home Haemodialysis setup uses 120L of water per hour.

The most common nocturnal home dialysis treatment regime is for 8hrs, 6nights a week, plus an hour for setup and disinfection procedures each day. This equates to 337kl of water consumed by the machine per year.

At the current water charges of \$2.20/kl, this equates to \$741.40 per year, \$477.40 more than the \$264/yr rebate proposed by SVC. Under the former Tumbarumba policy, this total amount would have been rebated.

I also note the arbitrary manner SVC have determined the proposed rebate – taking the mid-point of the reported NSW rebate range of 80 to 400kl, and halving it. Effectively saying they wish to be half as generous as the median.

Even the median only equates to \$528/yr. Less than half the \$1200/yr rebate I received in the ACT, which also had significantly more generous electricity rebates than NSW.

Electricity and water are not the only costs incurred by patients, which includes travel for appointments, time off work and medications. It can be a costly exercise when living in the country, particularly when your ability to work is impacted, so the rebates do genuinely make a difference.

I appreciate the rebate that is proposed, but I would like Snowy Valleys Council to consider the real level of water use for Home Haemodialysis treatment and provide a policy like the former Tumbarumba policy, that accounts for the actual level of the water used by what is a life support treatment, as offered by many other jurisdictions in NSW and across the country.

As noted in the business paper, the financial implication for SVC is negligible, yet significant for those unfortunate enough to require it.

Please contact me if I can provide more information.

Regards,

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### **Background**

Chronic Kidney Disease (CKD) is one of the fastest growing health challenges in Australia. With an estimated 1 in 3 adults at risk of developing Chronic Kidney Disease. Kidney failure requires the life-saving treatment of dialysis or a kidney transplant.

For people living in rural or remote locations, Home dialysis may be the only feasible option, unless they wish to relocate closer to a satellite centre or renal unit to receive treatment. However, Home Dialysis does come with a financial expense for patients who require it, which for some people is a determining factor.

### **Advantages of Home Dialysis**

Home Dialysis allows patients, like myself, to stay and live in regional areas such as Tumbarumba, where driving to a Dialysis Centre 3 times a week would not be feasible nor result in me being healthy enough to work.

Without Home Dialysis, I would be forced to move closer to a treatment centre. Thus, it keeps people living in our towns.

The advantages of home dialysis to a patient are considerable and include:

- longer survival times
- decreased risk of exposure to hospital infections
- improved quality of life
- decreased health system costs

- enhanced opportunities for rehabilitation and return to employment
- greater independence and flexibility to perform dialysis at a time that suits the individual with CKD and their families/carers
- no time and cost issues associated with transport to dialysis<sup>1</sup>

#### **Individual Costs of Home Dialysis**

Home dialysis uses electricity and water, and requires other adaptations at home that can leave the person on home dialysis out of pocket. A 2011 survey undertaken by Kidney Health Australia found that 13% of patients not currently using home dialysis in Australia were prepared to do so. This increased to 31% if expenses were reimbursed<sup>2</sup>. Kidney Health Australia support the principle of 'no out of pocket expenses' for home dialysis.

#### **Water Usage for Home Haemodialysis**

Water is used to create the special dialysis solution to clean the blood during each dialysis session. Water usage depends on how long the individual needs to dialyse to be healthy.

On average a Home Haemodialysis machine setup consumes 120L per hour.

Dialysis must be done for at least 15 hours per week, usually in three sessions for survival. But longer dialysis, up to 42 hours per week in 5 or 6 sessions done overnight is encouraged in Home Dialysis patients as it leads to much better health outcomes and the ability for the patient to function as close to normally as possible.

The dialysis machine also must use water for cleaning procedures. Therefore it is estimated that Home Haemo Dialysis (HHD) uses 126 - 400kl of water per annum (variable by treatment regime)<sup>3</sup>.

Cost varies by jurisdiction, supplier and overall household consumption making exact costs for each individual difficult to determine. The annual water cost in Australia for HHD patients is estimated to be \$468 - \$2000.

A useful website that explains more about home haemodialysis is [www.homedialysis.org.au](http://www.homedialysis.org.au)

#### **Home Haemodialysis Water Reimbursements by State**

Water subsidies for HHD vary in NSW depending on Local Government areas.

The below table from Kidney Health Australia, correct as of 1 Jan 2015, show that the free kl for those on dialysis varies widely, even within each state. Only those living in Victoria are guaranteed to have all costs reimbursed. These costs were.

SVC propose to provide 120kl which is on the low side for Australian rebates. It also does not cover the amount of water used by the average HHD treatment (6 x 8hr sessions per week, plus 6 disinfection programs). I also understand that the policy of the former Tumbarumba Shire Council was for no-charge for water associated with HHD. Which could be verified by the medical practitioner completed the number of hours the

<sup>1</sup> Kidney Health Australia, 2006, *National Chronic Kidney Disease Strategy*, p. 77.

<sup>2</sup> Kidney Health Australia, 2011, *Consumer Perspectives on Dialysis, First National Census*, p.50.

<sup>3</sup> Kidney Health Australia, 2015, *Water reimbursements letter*

	Low income or concession Holder Water Government (* Not dialysis specific)	Dialysis specific water rebate from water suppliers (varies by and within each state)	Estimated average litres to pay for by concession card holder (variable by treatment regime)	Estimated average litres to pay for non-concession card holder (variable by treatment regime)
<b>NSW</b>	Up to 100%	Free 80-400kl	0	0-243
<b>Victoria</b>	<b>\$277*</b>	Free 168kl* plus hospital reimbursement	0	0
<b>QLD</b>	<b>\$120*</b>	Free 50-400kl	76-277	76-277
<b>SA</b>	<b>\$235*</b>	Free 180kl	0-143	0-143
<b>WA</b>	Up to 50%	Hospital reimbursement	0	60-150
<b>ACT</b>	Up to 68%	\$1200	0	0-100
<b>Tasmania</b>	<b>\$150*</b>	Free Up to 200kl	0-123	0-123
<b>NT</b>	\$265+ (individually assessed)	0	0-323	126-323

#### My water usage

I am on HHD, living in Tumbarumba. Currently I dialyse 4 times per week.

*The background information in this letter was supplied by Kidney Health Australia.*