

Session One:

Medicines Matter to the Patient

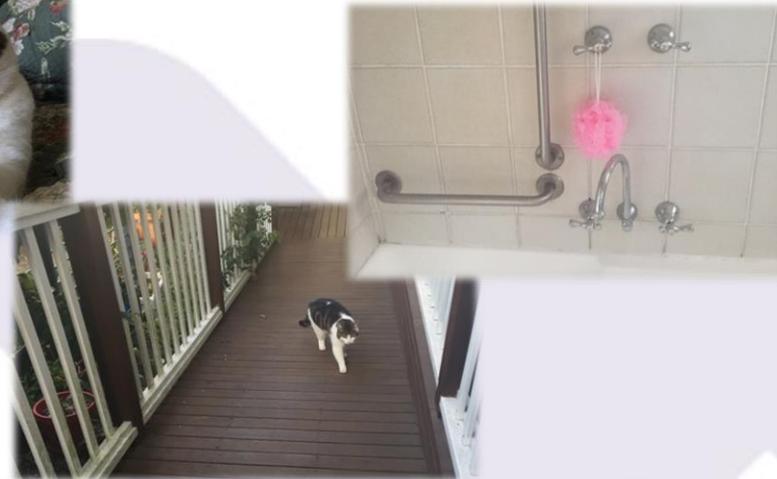
Who is the empowered consumer? What do patients want from a universal health care system and from the industry that provides medical and technological solutions?

Susan Hughes

Director, Dragon Claw

Susan's personal journey after being diagnosed with Rheumatoid Arthritis (RA)

My Village



My Passion - Travel

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21/8/2019
Re: Ms Susan Hughes
50 Goodlands Ave
THORNLEIGH
NSW 1513

Medications

Drug Name	Strength	Dosage	Notes	Last
BACEROBAN Ointment	2%	apply 3 times a day As directed		05/07/19
CRESTOR Tablet (Rosuvastatin calcium)	10mg	1 At night		27/06/19
DIABEX Tablet (Medometamil hydrochloride)	500mg	1 Twice a day		09/04/19
DYMISTA Nasal Spray (Azelastine (as hydrochloride)/Fluticasone propionate)	125mg/50	1 puff Twice a day 15 min before meals		10/07/19
ELOCON Lotion (Mometasone furoate)	0.1%	5 Twice a day		23/11/18
FOLIC ACID (NSGMA) Tablet (Folic acid)	5mg	1 In the morning		23/11/18
LYRICA Capsule (Pregabalin)	75mg	1 At night		23/11/2018
LYRICA Capsule (Pregabalin)	25mg	1 In the morning		23/09/2018
MARTEPEA Vial (Ezetimibe)	10mg/50mg	As directed		31/08/2011
METHOTREXATE Tablet (Methotrexate)	1mg	2-12 Weekly		23/11/2018
PRENISOLOONE Tablet (Prednisolone)	5mg	5 In the morning 3 days		
PRENISOLOONE Tablet (Prednisolone)	1mg	2-12 In the morning		

Mobility Parking Scheme
New South Wales, Australia

Susan Margaret HUGHES Card Number **2 044 140 662**

Category **INDIVIDUAL**

Susan Hughes Date of Birth **06 JUL 1953** Expiry Date **23 JAN 2024**



Rests- itinerary –



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Chutzpa – Invisible Disabilities



SOME DISABILITIES CAN BE INVISIBLE

• ANTHONY BREWSTER

With a valid disability permit, Susan Hughes parked in a disabled spot opposite Hornsby train station. Waiting to pick up her 87 year old aunt, she got out of her car, walked a short distance to check the timetable, and walked back and waited in her car for the train to arrive.

A man watching from afar then approached the car, walked around looking at the car and then proceeded to bang on the window and voice his opinion.

"How dare you park here! You haven't got a disability." He said while swearing and cursing as he stormed off.

It's not the first time Hughes has experienced this type of thing. Her disability, rheumatoid arthritis, is a chronic progressive disease causing inflammation in the joints and resulting in painful

deformity and immobility, especially in the fingers, wrists, feet, and ankles.

Hughes is one of around 400,000 people in Australia that suffer from the disease. The nature of the disease means that sufferers often don't need walking frames, crutches or any other visible aids.

To an observer, the disease is often invisible. For the sufferer, common daily tasks are often excruciating.

"Do we all have to resort to faking a limp, when we are in really excruciating pain in our skeleton and our muscles, just so people don't think we are there illegally," she said.

Recently, Hughes has become a member of a new organisation called Dragon Claw. Established in 2014, its aim is to provide a community for sufferers that will help them navigate

the health system to help them find services and support.

Its founder, Michael Gill, acknowledges there is a lot of discrimination in the community when it comes to these types of invisible disability. He also believes it extends into the workplace as well, compounding the effect of the disease. He believes the organisation is important, mostly for the support it provides to sufferers.

"The typical symptoms are extreme fatigue. They get very tired, very quickly. Stiffness, so in other words getting in and out of the car. Continuous or cyclical pain. On a bad day you can be staggering out of your disabled car park to go to do some shopping. On a good day you can walk normally. But then again on a bad day you might be able to walk fine but you can't



Susan Hughes at Hornsby train station where she was abused for parking in a disabled spot Photo: Anthony Brewster

carry anything very far. So a shopping bag becomes too heavy," he said.

"I think there is a reasonable amount of discrimination also in the sense of how people can't hold jobs down. Either because of the effects of the illness or because

the employer doesn't like to carry someone with a chronic disease," he said.

The organisation has set a goal of attracting over 20,000 members in the next five years.

For more information on Dragon Claw you can visit their website at:



Patients Helping Patients

Dragon Claw Charity

First Australians Patients



Summary

- There are not enough qualified R/A nurses.
- GPs and emergency staff are not conversant with the issues.
- Specialists are very hard to get to see promptly.
- Our disease is 'silent' and not visible, so the general public are often intolerant and ignorant to the invisible disability.
- Dragon Claw (DC) was created to provide support for patients and carers.
- DC is keen to partner with interested organizations to close the gap - RA Nurse program.