



Your Community Health Newsletter

THE CONSUMER EDITION

Waitakere Health Link bring health communities of interest together within the health sector and reach out across other social wellbeing sectors. We work closely with Waitemata District Health Board to connect health services in the west with consumers and disseminate health information to the community and collect feedback to inform service planning.

Consumer Health Literacy Review

Health Links host monthly Consumer Health Literacy meetings to review Waitemata District Health Board printed patient information and online to ensure they are easy to read and understand. The demand for this service has doubled in the last year and we continually receive positive feedback from authors who value the input from consumers to improve their communication with patients.

WHAT IS HEALTH LITERACY?

Health Literacy is about being able to **receive** information, to **understand** that information and be able to **act** on it.

For healthcare consumers health literacy means:

- Understand appointment slips
- follow doctors instructions after a visit
- Understand how to take medication properly
- Read and understand educational pamphlets
- Know when to call an ambulance, or the doctor or visit the hospital.
- Knowing what to do before you go to hospital
- Read and understand forms such as consent.
- The ability to give informed consent for the direction of your health care
- The ability to navigate the complex health system

For more information phone us on 839 0512.

FROM THE CONSUMER PERSPECTIVE:

- "We need to simplify written material so that everyone is able to read and understand it."
- "The work we do helps untangle Doctors and Nurses information, making it easier to understand. Being part of the Health Literacy Group makes me feel I have contributed to improvements in communication between the Medical Community and Patient Community."
- "As health consumer representative, I ensure that health materials are simple to read, easy to understand, and culturally appropriate to our pacific people."
- "I have enjoyed being able to voice my thoughts and opinions freely. I am gratified to find my suggestions have been useful for patients by providing easier to read information."
- "We are all looking for information about our health, but so much that is available is written in language that is complex and too scientific."
- "Pictures are really important to me as I am a visual learner - great to be able to repeat that again and again."
- "We don't all understand the same way and it is critical that time and willingness to think about what a patient would really need from a document: that makes my day."

FROM THE HEALTH PROVIDER PERSPECTIVE:

- "We find the health literacy group to be really helpful. As a clinician we know what we want the consumers to know and often think we know how. Having a representative group of consumers often highlights queries and or misinterpretations that we had never considered may occur, this allows us to adjust wording or format to remove confusing words and or ambiguity."
- "Really constructive and helpful feedback that confirmed we were on the right track - but also gave voice to a few other things we hadn't thought of"
- "As clinicians we know what information needs to be on the leaflet but we are perhaps not so good at making it reader friendly. The suggestions have ensured that the language used in the leaflet is accessible, important information stands out and is easy to read"
- "We have changed the leaflet quite extensively in response to your feedback and I have to say it's definitely for the better"

Waitakere Health Link is a community driven organisation committed to improving health in West Auckland by promoting community participation in healthcare decision making and fostering collaborative relationships between healthcare providers and the West Auckland community.

THE ISSUE BRINGS YOU:

- Consumer Health Literacy
- Consumer Participation
- Patient Participation
- Consumer Stories
- Toddler Day Out

Consumer Participation

Waitakere Health Link believes that genuine effective consumer participation is a necessary part of a patient-centred health care system, and can play a vital role on many decision-making and advisory bodies and add value to outcomes. Consumer Representation ensures that these bodies have access to a wide range of views.

WHAT IS A CONSUMER REPRESENTATIVE?

A consumer representative is a committee member who voices the consumer perspective and takes part in the decision-making process on behalf of consumers. This person is usually nominated by, and is accountable to, an organisation of consumers. Being a consumer representative may take a number of different forms, including participating:

- In research projects, forums or focus groups
- Meetings where policy is developed and/or action plans devised
- In evaluation of services provided
- In development of educational material
- On a range of committees including advisory committees or regulatory bodies.

Waitakere Health Link and Health Link North have historically provided a Consumer Representative Training Programme for people interested in becoming Consumer Representatives.

Recently the Health Quality and Safety Commission has launched a new guide for training health and disability consumer representatives which will standardise this training nationally. Health Link North Manager attended the initial training to become a regional facilitator.

The guide includes four training and education modules and a series of lesson plans to help facilitators deliver the training, including: Health and Disability Context, Experience Base, Evidence Base and Partnership. There is increasing evidence of the link between consumer participation and clinical effectiveness.

For more information phone us on 839 0512.

The Waitemata District Health Board Quality Use of Medicines Steering Group

FROM THE HEALTH PROVIDER PERSPECTIVE:

"The Quality Use of Medicines team at Waitemata DHB are fortunate enough to have an excellent consumer representative on our Steering Group. Judith helps us to put consumers at the forefront of our work, and constantly think about how we can make things simpler and easier for them while they are in our care. We are here to support and improve the experience of consumers; we need consumers to remind us of this."

FROM THE CONSUMER PERSPECTIVE:

"I have had a long time commitment with the Quality Use of Medicines group and at times I go to meetings and feel I add nothing but at other times I have the opportunity to bring the wider community and their needs into the room and this makes it all worthwhile. The role has grown as has the importance of Consumer representation. Now the acceptance of the Consumer Representative is not a struggle but a normal procedure. What great progress." Judith Lunny

The Auckland Regional Dental Service Clinical Governance Group

FROM THE HEALTH PROVIDER PERSPECTIVE:

"Over recent years the Oral Health Service has undergone significant change in both infrastructure and models of care. Following the changes, the necessity for consumer representation was raised. The catalyst for change was a credentialing process that highlighted it as a gap for our service. ARDS now engages two representatives. It is really important for services to maintain the patient at the forefront of their decision making, the representatives enhance this process. It is invaluable to have input on a regular basis from people who, either use or have recently used, the service. The main driver of the service is the children i.e consumer and their parents'/caregivers'. Their participation in the decision making process is of paramount importance. Consumer representatives have an independent view not influenced by the service, work force and finance. This view will have positive impact on overall service strategies particularly on communication, accessibility and cultural appropriateness in providing acceptable and appropriate care to the population at large."

FROM THE CONSUMER PERSPECTIVE:

"It has been a steep learning curve with the terminology and experience in the room. My questions are welcomed even when they are basic and general knowledge. Sometimes we all learn more from the answer. I think through the ability to ask a question purely from a parent, end user, thinking about my children and their needs point of view: this can refocus how things are considered at times in the meeting. This also reflects in thinking about how other parents/care givers and families might feel and being able to represent this when in the group." ARDS Clinical Governance Consumer Rep

A CONSUMERS PERSPECTIVE



Some years ago I was invited to be consumer advocate a role that has grown over the years and always proved to be very interesting and

forever a learning experience. It began as being part of consumer training and health literacy. Since then the role has been varied from sitting on the judging panel of the Health Excellence awards to the very amusing and entertaining afternoon portraying an elderly lady who suffered an adverse event for an educational

video. For some weeks I was part of the team who worked on the Adverse Events of Using Opioids after Surgery. A great project that was a lot of work but made with some very friendly people and it was wonderful to part of such a committed team. Just one of the many experiences I have been fortunate enough to have.

Judith Lunny

Patient and Family Participation

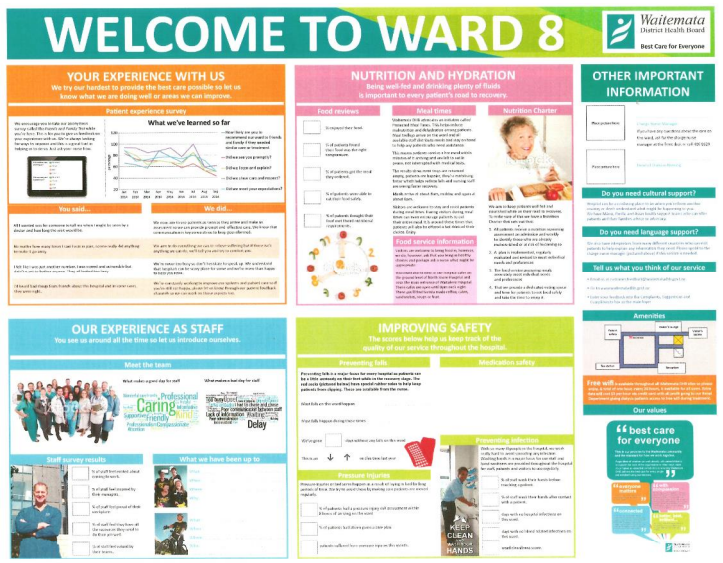
One of the Waitemata District Health Board's top priorities is to improve the experience of people using health services. Our organisational promise is to provide the best care for everyone so over the last year a lot of work has been undertaken to make sure patients, their families, and the wider community have better access to information, and are able to influence the way services are provided.

IMPROVING PATIENT EXPERIENCE AT WAITEMATA DISTRICT HEALTH BOARD

PATIENT INFORMATION

The DHB works closely with Waitakere Health Link and Health Link North, and their consumer health literacy review groups to ensure that all public information is written in a way that people understand. Recently this has involved working to design the DHB's new website, which will go live in early 2015. The new website will include all the things the community needs to know - things like how to get to hospital, parking, what to bring, the facilities available in hospital, and what happens when you go home. In addition every ward will be getting a new 'quality

board'. These boards have information about how we monitor the quality of services, and what we are doing to improve. The boards also have important information such as contact details for the Charge Nurse if patients or visitors have any questions. During December the new boards will be displayed on Wards 2 and 8 at North Shore Hospital, and Anawhata Ward at Waitakere Hospital. We will be collecting patient, visitor, and staff feedback on these boards before they are printed for every area in the New Year.



If you happen to visit those areas in December please take some time to look at the quality boards and give us your views.

PATIENT AND COMMUNITY FEEDBACK

Feedback from patients, the community, and staff is the best way for Waitemata District Health Board to understand what works well and what needs to change. For the last year we have been using an anonymous electronic survey in the wards called the 'Friends and Family Test,' to learn about people's experience of hospital services. More recently we have started to create a library of patient stories on video so that staff can learn directly from the people using their services about their experiences. The videos are short 4-5 minute

films of patients and their loved ones talking about what matters most to them, what the Waitemata District Health Board does well, and the things they would like to change. Some of these stories also have messages to other patients and the community to help others learn from experience. Many of the stories will be available on the new website. We welcome and encourage feedback so if you have a story to share, or are using Waitemata District Health Board services, please feel free to ask a staff member to complete the Friends and



Family Survey or put your feedback in the feedback booths that are located in the reception area of Waitakere and North Shore Hospitals or provide your feedback online at www.waitematahdb.govt.nz

HAVE YOU BEEN INVITED TO PARTICIPATE IN BOWEL SCREENING?

Staff at the bowel screening pilot are urging anyone in the Waitemata region to get in touch if they haven't been sent an invitation and test kit to check themselves out. Bowel Screening community awareness team leader Elizabeth Brown says bowel cancer is now the most commonly diagnosed cancer in New Zealand, and the

second leading cause of death from cancer. The pilot has detected cancer in 184 people so far. Waitemata District Health Board residents who are aged 50-74 and who are eligible for publically funded health care can participate in the bowel screening pilot. Latest figures from the pilot show around 54 percent of

people invited to take part in the pilot have returned a completed bowel screening test. Miss Brown says while that figure is good compared with similar pilots internationally, she is concerned many people who want to take part are missing out on this unique opportunity. **Phone 0800 924 432**



CONSUMER PARTICIPATION EDITION

TO:

Ensuring the community voice is heard in healthcare decision making.

Waitakere Health Link, PO Box 21 852, Henderson 0650. Telephone: 839 0512.
Website: www.waitakerehealthlink.org.nz Email: office@waitakerehealthlink.org.nz

Consumer Stories

Consumer participation stories from around our community...

HOW THE INTEGRATED NEUROLOGICAL REHABILITATION FOUNDATION HELPED ME



My name is Kirk Wallace and I've been attending Conductive Education classes for nineteen years. In February 1995 I suffered a moderate / severe stroke without any warning. I was paralysed down my left side unable to stand or even sit. I heard about an organisation that is now called Integrated Neurological

Rehabilitation Foundation. After meeting with the conductors at INRF, I just knew this was the best place to be. Conductive Education has helped me immensely, physically and mentally. I can't speak highly enough of the benefits I have received. I went from walking with a stick to walking independently, I gained confidence,

and it gave me the motivation to start driving again. Over the years I have learnt many techniques and skills to help me in my life. I continue to attend is to maintain that ability and flexibility. My advice "After a stroke there is a dark tunnel and Integrated Neurological Rehabilitation Foundation is the light at the end".

WALKING AND COMRADESHIP BY MARGARET WILLOUGHBY

My husband and I have been a part of the Alzheimer's Auckland Orewa walking group since February 2014. We meet every Wednesday come rain or shine at the Te Ara Te Huna Estuary walk way in Orewa. There are various routes that we choose to walk with some happy to do just a short walk, and have a chat, while others stride out and complete a longer course. The walk is part of the support network set up for carers and anyone suffering cognitive impairment under the auspices of Alzheimer's Auckland.

Right from the start we were made to feel very welcome and my husband who has been a bit isolated at home since being diagnosed with Alzheimer's loves walking so this was an ideal activity for him. He immediately made friends especially with 2 others in the group and they have formed a special bond looking out for each other not only on this walk but when attending a rehab group together every Friday. They have become known as the "Three Musketeers". The wives and partners of those attending the group have also become friends

and often assist the dedicated volunteers who come along each week to lend a hand and ensure that everyone has a good time and arrive back safely to the very popular Driftwood Cafe for a delicious morning tea. The cafe go out of their way for us setting up tables for us so we can continue with the conversations and laughter that commenced whilst out walking. These weekly meetings have become a welcome respite for all who attend, an opportunity to share and seek reassurance from others who are experiencing



the same difficulties as yourself. Our thanks go to the Alzheimer's Auckland workers and volunteers who have made this group such a success.

Toddler Day Out—Sat 7 March 2015

Toddler Day Out and the Great Parenting Fair is on again at the Trusts Stadium Arena between 10am and 3:30 pm. It is always a welcoming and wonderful event, and some of what was so magical last year was the village theme, where different cultures and services created an area of interaction, activities and conversation. There are always lots of great things for families with children under the age of five to do ... learning and play activities, art, dance, exploration of everything from healthy diet to imaginative places to play in. Mums and Dads have a great time too...

Check out our facebook page 'Toddler Day Out - West Auckland' for more information if you are thinking of coming!
Please contact Kay Lindley kaylindley@xtra.co.nz or Robyn Brady admin@violencefreewaitakere.org