Keeping Seniors Well

Community Engagement Summary

July 29, 2015

BACKGROUND

Sometimes seniors, with difficult health conditions, may end up going to an emergency department for health care because they are unable to get the care in their home community that meets their needs. We know that for seniors, home is often the best place to manage health conditions, recover from illness, and live out their final days. Vancouver Coastal Health and providence Health Care are committed to delivering quality health care services in the most appropriate care settings.

Health Authorities in the province have been asked by the Ministry of Health to develop a better approach to providing care for seniors with difficult health conditions. At Vancouver Coastal Health and Providence Health Care we want to start with the Vancouver West End/Fairview Slopes area. The goal is to develop better ways keep seniors well in their home and community. We want people to experience a better quality of life.

In order to do this Vancouver Coastal Health (VCH) and Providence Health Care (PHC) need to hear from patients, their families and their caregivers in order to inform a new model of care.

COMMUNITY ENGAGEMENT PROCESS

Community Engagement (CE) was asked to support engagement of seniors, and their families in order to inform a model of care that provides for the needs of seniors and keeps them safe and healthy in their homes while reducing the need for them to go to the emergency department for care.

We wanted to hear their experience and what their needs are. A series of three forums were planned in order to have a conversation with seniors, their families and those in the community that provide care and support to them. The goal was to understand what their care currently looks like, and hear what is needed to provide better care. With this input VCH and PHC are intent on the development of a new model of care that will better meet the needs of seniors.

The first forum held Wednesday, July 29, 2015 had an attendance of 52 people with a mix of seniors, their family members, community agency representatives, physicians and health care providers.

The forum began with participants being asked to identify their current needs in order to stay safe and healthy in their homes and not need to seek care in the emergency department. The needs expressed were then themed into topics of discussion, which all participants were involved in, with each participant having the opportunity to discuss three topics during the forum.

Clients, patients and family caregivers that could not attend the forum were invited to share their stories and care needs via one on one discussion either by phone or in person. Ten individuals participated and shared their feedback through this option.

SUMMARY of DISCUSSION

This is a summary of the discussion, grouped under each of the main topics, as decided on by participants.

Gaps in Clinical Care

Location

- Location of services such as nursing care is not located close to where patients live. Suggestion: have location of services to be in the same building with nurse available
- The moving of St. Paul's is a concern – how to travel to new location?

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Transportation

- It is difficult to get to appointments as transportation is not always available
- People live alone and are lonely and fearful they need scheduled calls or a telephone buddy
- "I lived in North Vancouver for a number of years, moved to West End but could not find a
- doctor so had to go to my doctor in North Vancouver. Handydart does not go across the bridge to N. Van. To take a taxi back from the doctor I paid $59.00 which I can't afford".
- Since I visit many specialists (urologist, gastroenterologist), I just sit and wait for Handydart for majority of the time.
  (feeling lonely)
- Transportation to a dentist or to get my hair and nails done would be lovely. I really need foot care but can't get to the specialist on Broadway.
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Specialty Services

- Clinics are good, but they cannot replace hospital – gives more confidence, specialist services available
- Lack of palliative care services
- Gaps in care for people who are disabled, particularly when they are in hospital and discharging out to community
- Need for care workers with mental health skills
- Home care workers are not trained in mental health and complex care management
- Lack of education from different specialists to take correct prescriptions
- need care providers who come to the home to have medical training
- I need to take my dog to the vet from time to time, nobody can take me there. I have nobody here – only son in Europe who cannot travel here and I cannot travel to Europe
- "When I go for my kidney care I get good care but I am like a car just a collection of parts. No one asks about the whole me"
- My doctor came to see me Friday and referred me to a specialist for my feet but it is too hard to get there. "My feet hurt so much it feels like I am walking on bone"
- What do I need – "I need to die, do you have one of those pills you can give me."

Affordability

- Cost of medications makes it hard to afford
- Cost of vaccinations are hard to afford
- Need some subsidy for food
- Inadequate laundry/cleaning services
- I need my laundry done to be able to stay home this is part of health

Access

- Being put on a waiting list is a barrier to care. they are wasteful, expensive, hard on people
- Gaps in care when transferring from St. Paul's to Fraser Health
- No access after 5pm in clinics
- Need to have more student nurses and trainees to fill the gaps
- Nurses should take blood pressure, don't want to bother clinic
- Have health monitoring services available at community centres
- Need to have clinical care and other services provided close to or in my home to keep me home
- Lack of access to computers to get information that is online
- Broadway building (750 W. Broadway) does not have ramps and it is impossible to get off the sidewalk when visiting my specialist.

Transitions

- Coordination problem (different service providers not talking to each other)
- Negative experience at elder's clinic at St. Paul's, it didn't meet needs, it was like "speed-dating" through different services provided, did not have structured activity, socialization of seniors, transportation arrangements, did not simulate an adult day center experience
- Need better co-ordination – Clinician to be part of the discharge planning from hospital

- Currently a lack of integrated care where doctors, physiotherapists, dieticians come in each day of the week to provide their services
- Need for case management

Downloading to Community Agencies

Better at Home

- Currently Better at Home has 2 categories: 1) free 2) pay if you cannot pay then you have to wait
- VCH refers clients to Better at Home but don't tell them they have to pay
- for low-income people priorities are rent and food, cannot pay physio, dental and other health services
- I am being asked to list my name with Better at Home or I will lose home support but if I list with Better at Home I have to pay and cannot afford to wait over a year for services.
- Clients were redirected to community agencies but client not told that they need to pay; clients often cannot afford to pay. VCH then cut Home Support services
- Better at Home has long waitlist unless you can pay
- There's a lot of bad debt incurred by seniors for Better at Home or Safeway shopping as seniors often can't remember they ordered or used services. This debt is carried by community agencies.
- Better at home – non medical but supports have health implications

Cleaning, Laundry and Other services

- Health is downloading services such as laundry, cleaning
- Services have been cut so clients not getting services because they are not able to pay – dirty clothing, dishes, dirty apartment
- What is needed is help with heavy work around the home but now only help with light work is offered for a fee
- Need support with shopping and to bring groceries up to their home
- I would really like to have laundry done more often but I can't afford it.
- I would love to go shopping with someone and be able to pick out food. I cannot remember the last time I went outside

Advocacy

- clients can't advocate for themselves
- Health Authority staff are unionized but now same services are downloaded to women who receive even less pay
- Downloading is also occurring to volunteer/caregiver
- NGO/community agency caregivers can only offer low paying positions compared to VCH Home support which makes it hard to find people to work
- Community agencies do not have the skilled staff to support seniors who have become more complex with physical and mental health needs
- Clients need to be case managed because they have complex needs

Consultation

- NGOs were not consulted when home support services were cut
- Community agencies – need to have capacity and funding to support seniors

Communication

- Gap in collaboration between VCH and community agencies

Family caregivers

Resources

- Need more information freely and frequently provided to families by home care staff on programs such as Assistive Devices Program, respite beds, these should not be kept secret. Case managers could easily volunteer information about them.
- there are lots of programs but it is hard to navigate and know what you are allowed to access
- CSIL program is a bureaucratic nightmare

- Family and Friends need some resources/service – they need support (emotional, educational, home support)
- Need support and training for family
- Need a mechanism for sharing information and skill among families
- Need to provide community education about aging
- Use technology for support
- Need to have options for Community centers and libraries as being resources for caregivers
- Family caregivers need to be given information in writing so they really knew what's going on with the care recipient
- Need clear language as it relate to services and support for clients that family caregivers can understand and access. Too much jargon, not enough plain English

Advocacy and Support

- Family and friend involvement can help keep frail seniors out of hospital. Families may turn to care in Emergency departments , hospital and residential care because they are burnt out
- "if something happens to me what will happen to my partner? We have no family."
- I need a contact to call in the event that I need help
- VCH eliminated its Family Caregiver Program last year – now there is nothing
- Family caregivers need to be well valued and acknowledged versus overloaded or ignored
- Does anyone actually ask family caregivers "how can we help you?" adhering to family centred care practice
- Doctors don't family caregivers "how are you doing?"
- Family caregivers want to be a daughter, a son in law, not a 24/7 nurse/service provider
- Caregiving is huge responsibility for the family
- Decrease family isolation
- Family caregivers are getting older too
- Increasingly people have no family members to care for them. Some are from the LGBTQ community or have low income or limited English
- Family caregivers can sometimes advocate for their loved one but also need to advocate for themselves
- Need managers trained to ask family caregivers how they are doing and what supports they need.
- Need to encourage family caregivers to care for themselves
- "I have been a caregiver without a break for 8 years now. I am tired. I need support. "

Clinical Care in Home

Consistency

- There is a lack of consistent care among the various caregivers
- Clients not able to create needed and valuable relationships with caregivers
- Lack of consistent triage/ care team models
- Need to improve linkages or reduce the number of staff involved to create coherence
- once a week a nurse comes to change my dressing but only once a week and this is not very often . I am worried that my grandson will come and find me dead for 7 days maybe there is such a thing as a computer that people dial in to that confirms the person is still alive and ok.
- "My biggest challenge is fear of being by myself – now I have a lifeline but would be better if someone checks on me."
- "My home support person gets upset when I ask her to do certain things. The care workers do not seem to work out for me they take offense ta things I say or don't understand me. It is not easy to find good people even if you hire them they steal from you."

Access

- Cut back on seniors – lack of Instrumental Activities of Daily Living support
- Each block should have caregiver parking
- Need greater access to clinical care in the home

- "I need a place to go that is near my home and has a range of activities that allow me to be part of the community"
- Need doctors to do home visits
- Need some support with my equipment, I have a wheelchair which was rent to purchase, but I would like to own some modern equipment that could help with my mobility.
- "If and when someone is ready to die – should be able to have a pill from the doctor".

Communication

- Lack of communication from care management
- Care managers don't communicate with other care providers
- My case manager says he is too busy to come over.
- When a senior is discharged from hospital it is very difficult to contact a health care provider to get information
- Need good relationship with family doctor
- Need to establish and encourage relationships with physicians and other caregivers
- Seniors have pre-conceived ideas about what emergency departments can provide and see these as safe when they are scared

Funding Structures and Task Focused

Timeliness

- Services are not available when you need them
- Have to make many phones to locate service, have to stay on hold, too many choices on the phone make it very confusing
- Need to have human beings back on the phones when seeking services. The multiple recordings are too confusing.
- Need to wait several days for meds due to lag in services

Appropriate Services

- Don't limit health care services because a family member does some work
- If you qualify for Home care at VCH then don't direct the person to Better at Home services
- The care of a family member should not be factored in to the system providing services
- Health care providers acknowledge that what the client is eligible for is not always what they need
- Current home support is very task focused and does not take into account the needs of the senior
- A senior may be eligible for personal care but they really want cleaning but they are not allowed to receive this
- Timing restricts delivery – need to have more focus on a given time to deliver support needed as opposed to completing tasks

Cost of care

- Seniors just above low income have an unreasonable cost burden – eg. A cost of $5K for oxygen machines and wheelchair – seniors are challenged to cover costs
- Seniors have various levels of health insurance coverage but not everyone knows the system and it is not easily navigated
- The government has redirected services and the related costs by out-sourcing with lower wages
- Calls to access service can take a long time and the cost of the call when you have a pay as you go phone can be quite costly. Also some seniors don't have access to a phone.
- Funding sources are fragmented and don't help seniors get what they need when they need it
- Patients that need cleaning can't afford to pay for it as well as eat
- Clinical people and clients don't understand how funding works and what certain service costs- need to understand what services costs
- Related to funding structures we need to insist on accountability

Collaboration

- Better at Home community services working in conjunction with VCH is lacking, there is need to have better communication with Better at Home to be part of team of care providers
- Need to use space available in buildings that isn't being used to offer services
- Services are not coordinated even when a senior has to pay for it

Transitions from Hospital

Coordination and Communication

- Need for better coordination
- Need to improve the communication between the GP on admission and discharge
- When a person is discharged on a Friday there are no community supports available over weekend
- Need to have more/support from GP to assist in the transition
- Need to ensure medications are ready and will be provided on discharge
  No coordination support for those who struggle with following through on instructions
- Hospital not planning early enough for discharge and should have visits to home to prepare for discharge and ensure all is ready and in place to support a good transition to home.
- Concerns with patients are not communicated to community supports before discharge
- Lack of e-records across systems
- need to reduce silos of care
- GP's don't hear about their patients experience in hospital. Connect with GP as part of discharge plan
- Need a phone meeting with receiving facility
- Need to minimize the number of providers and increase communication
- When time to discharge the case manager in hospital is not same as in the community
- Need to create a way to communicate information about a patient in a way that reduces the loss of information as message is translated or shared

Timely and Appropriate Care

- Need increased services for convalescence and rehab when moving from hospital to home
- Need to focus support on first 24-48 hours after discharge to ensure successful transition to home
- Health care/Hospital needs to communicate with community supports 2-3 days prior to downloading
- Discharges are often too late and result in additional supports being required or too soon resulting in readmissions
- Discharge planning starts too late in the hospital. Need to start when the person is admitted.
- Rehab should be set up prior to discharge
- The default place to go for care when things don't go well is the emergency department

Resources

- Assisted Living has complex policies related to access
- Seniors don't know what services they can receive so they don't have to go to hospital
- Assisted living can't be accessed from hospital
- Too many people in the hospital doing team care planning and no one makes decision

Clients Having to Pay for Services

Advocacy and Support

- Needed to find someone that could look after a parent, had to be very assertive to get the services needed
- Seniors don't want to go to hospital they just get too overwhelmed
- Life is becoming very difficult for me – small chores such as pouring cereal into the bowl is difficult.
- "The services of an occupational therapist would be appreciated. I find myself having to pay

someone to walk with me. I am not looking for a job but I do want a meaningful existence"

- I have no one, no family members, my family is in Europe but I cannot travel there. They are unable to come visit me as well. I was a caregiver of a lady friend who is currently in a care home, and now I can't even go visit her due to transportation issues and my own chronic conditions.

Access

- Started to look for someone to make bed 5x/wk -> couldn't access this service
- need more help cleaning because he couldn't do it anymore
- GP – too far to travel to and have to pay for cab
- Has had someone in to clean & he stole from him
- Receiving service but very fragmented & multiple services that are disconnected
- Some services such as Home Vive / Better @ Home) get overwhelmed so not everyone that needs services get them
- There are restrictions on getting services as they don't look at needs of the patient

Consistency of Caregivers & Home Support:

Timeliness

- Not enough time to complete tasks or get to know needs of client or their routine

Access

- People do not know what services are available and who to contact to get them

Coordination

- Need for effective communication between case manager/supervisor/caregiver/client
- new or different or constantly changing health care providers cannot see detrimental changes in health of client

NEXT STEPS

This feedback will be used to support discussion at the next forum on the topic of ***Defining Better Care***. This forum will be the next step to determine what better care could be for seniors with difficult health conditions. The next forum will take place August 12th.

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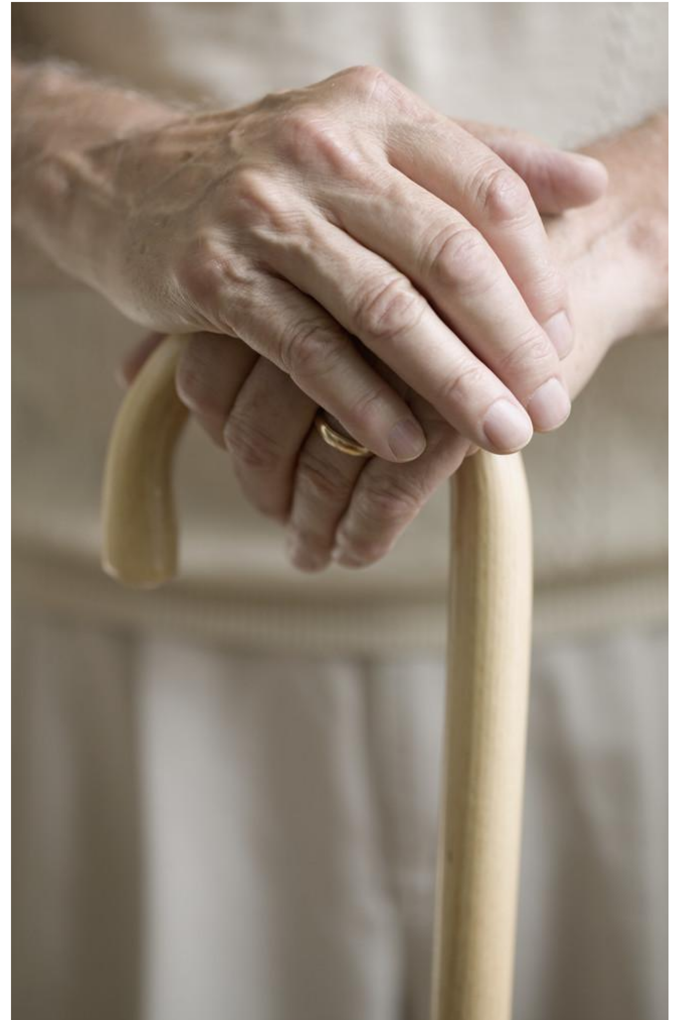

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Vancouver Coastal Health,
August 4,2015

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Keeping Seniors Well in the Community

An Invitation to Develop a Better approach to Seniors Care in the Community

Sometimes seniors, with difficult health conditions, may end up going to the emergency department for health care because they are unable to get the care they need outside of the hospital. We know that, for seniors, home is often the best place to improve their health, manage health conditions, recover from illness and live their life. Vancouver Coastal Health (VCH) and Providence Health Care (PHC) are committed to delivering quality health care services in the most appropriate care settings.

Health Authorities in the province have been asked by the Ministry of Health to develop a better approach to providing care for seniors with difficult health conditions. At VCH and PHC, we want to start with two communities: the North Shore and the Vancouver West End/Fairview Slopes area. The goal is to develop better ways to keep seniors well in their home and community. We want people like Estelle (read Estelle's story) to experience a better quality of life.

In order to do this VCH and PHC want to hear from patients, their families and their caregivers. We want to hear about their experiences in the health care system, what is working well and what they see as gaps and opportunities for improvement. We are planning a series of three forums over the summer, to have a conversation with seniors, their families and those in the community that provide care and support to them. With this information we will develop a new way to provide health care. We are asking you to be part of this planning and development process by attending all three upcoming forums. Your involvement and input is important at all three forums as we build towards a new model of care.

Please consider attending all three forums:

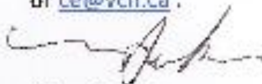
- *Understanding the Care Experience Forum* - **Wednesday, July 29th from 9:00 am until 12:00 noon.**
- *Defining Better Care Forum* - **Wednesday, August 12th from 9:00 am until 12:00 noon**
- *Confirming a New Approach to Care Forum* - **Wednesday, August 26th from 9:00 am until 12:00 noon.**

We hope you will attend and will find this opportunity as exciting as we do.

If you are able to attend these forums, please **RSVP by returning this email or calling 604.714.3779.** Please include in your reply, your full name, organization (if applicable) and phone number. Details of the location will be provided upon confirmation of your attendance.

If you are unable to attend but are interested in sharing your health care experience and ideas please contact Belinda Boyd, Leader, Community Engagement at 604.714.3779 or ce@vch.ca to arrange time to share your ideas with us.

If you would like more information or have any questions, please contact VCH Community Engagement at 604.714.3779 or ce@vch.ca .



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Keeping Seniors Well in the Community – A Story

July 9, 2015

Hi, my name is Estelle and I am 79 years old and I live alone in the West End of Vancouver where I have lived for the past 26 years. When I moved here, I was a very active 53 year old, still working and very involved in my local community. I am still involved as much as I can be, but am now retired and a lot less active. I have lived with Type 2 diabetes for the past 9 years and, just 3 years ago, developed Chronic Obstructive Pulmonary Disease or COPD. The change in my quality of life has been hard to adjust to. I find I am afraid to go out much because I have trouble catching my breath and often feel tightness in my chest and a general lack of energy. The constant coughing also adds to my incontinence so I am always worried about not being near a washroom. I am on a limited income and cannot afford to buy adult diapers.

My world has gotten so small. I am not able to join in the many activities that I used to and I find I am often scared to be alone because of the COPD. My daughter lives in Toronto; I know she worries about me but even if I did phone her, what can she do to help me from 2,500 miles away? Sometimes I have these coughing fits and can't catch my breath, which is very scary. I usually end up calling an ambulance when that happens. Most of the time, they take me to St. Paul's Hospital Emergency. At the hospital, I often have to wait a while to see a doctor. This can be a problem because while I am waiting, I can't have anything to eat or drink and they don't give me my insulin. By the time I see the doctor, I feel worse than when I arrived. The most difficult part is getting home. My partner died 8 months ago and, with no family nearby, there is no one to call to come and pick me up. I find this embarrassing so I don't share this with the emergency staff. When I am ready to go home, I tell the staff that someone is coming to pick me up and I wait in the lobby for a cab. I can't really afford the cab but I know I can't make the walk to my home. I need something to eat and drink but, again, can't afford to buy something to eat and also take a cab so have to wait to eat until I get home.

This has become my life. I feel trapped and not sure how to get past this cycle of being unwell, getting worse, going to the hospital and feeling even worse. I don't have anyone to talk to about this. I do have a wonderful family doctor but she is very busy and I don't go to see her unless I really have to. Also she moved her office recently and it is further away so I can't walk there anymore and now have to take 3 buses to get to her office. It is not easy with my COPD to climb up and down the bus steps. Also there is often not any seat on the bus and I don't want to shout "hey I have COPD, can someone please give me a seat!" Taking a cab just isn't in my budget. When I do see my doctor, she has limited time to listen and I am not really sure what she could do to help me any way. I really want to have a better quality of life. I know I will always have the diabetes and COPD but I want to find a way to live with them and still be able to participate in life. I don't want my only trips out of my house to be to the hospital or the people I see most often to be the ambulance people or emergency staff. I remember what it was like to have a life and I want to experience that again.