Alzheimer Journey Legend: Gaps and Solutions

1 Person and or family suspect a problem but either fear or do not know what to do
2 Philosophy of care and set of guiding principles
3 Information on legal planning/representation agreement Representation Agreement Resource Centre 604-408-7414
4 Info should be available on Nurse Helpline
5 More education of affiliated service provider for early signs
6 Need to routinely screen for dementia like we do for diabetics, heart disease, etc.
7 Support for GP from motor vehicle branch to test for driver license
8 Fund medications to RX Alzheimer's & related dementias via PharmaCare program
9 GAP Alz Society need s to heavily advertise "NOT JUST FOR ALZ DISEASE"
10 GAP Most knowledge about early identification/early intervention is in the specialist group, but the major clamour for services of the specialists in management of problems in mid-disease
11 Possible Solution – targeted training of GP/NP in early identification and measures to delay (brain exercise, nutrition, supplements, decreased alcohol, etc)
12 GAP "Geriatric Psych" services age limited to greater than 75 years
13 GAP reduced access to home support early in disease process. Can no longer provide service that is primarily for monitoring
14 Education: focus on the application of knowledge/practical experience caring for persons with dementia is complex
15 No System based IADL support (not HS), now volunteer driven, very limited and fragmented.
16a Need to improve ability and capacity of housing providers to understand and meet needs of people with chronic illness at all levels of housing.
16b Health and housing working together.
17 GAPS: cognitive intervention and mental health promotion
18 Need standardized province-wide education programs for all residential, community and acute care staff.
19 GAP: Need dementia education for the Volunteers in the system e.g. MOW, Friendly Visitors.
19a I agreed! "To allow risk" is inappropriate language. Consider using "Dignity of risk".
20 GAP Behavioral crisis. Lack of short term assessment and treatment beds across province.
21 GAP Community – Need more Community Health Workers – Need to have them hired as employees, not piece meal work (UFCW Contract) – need education and support.
22 GAP need specialty dementia programs for ADP. (More weekend/late afternoon/ Sundowning activity)
23 GAP: Heavy community caseloads prevent regular reassessments of client/caregiver needs.
24 Health Service Guidelines are about money and rules not meeting individuals' needs.
25 Please use term ADULT Day Centre or Program – NOT Day Care – clients hate it.
26 Gap Wait List for ADP X weeks – months.
27 CTS/caregivers should be able to customize help to suit needs.
28 Name on facility waiting list. ----This no longer happens unless private pay.
29 GAP/Solution: night respite (model in Manitoba) e.g. Use a day hosp. or other community space to care for individual disordered with dementia at night so care giver. can sleep.
30 Eve and weekend programs.
31 Application of home support for respite/caregiver support varies by health Region and HSDA.
32 VON 24 hrs, respite congregate care.
33 GAP a review of personal values important before moderate, less communicative stage example; autonomy vs. burdening, home vs. care
34 More general education for community on this.
35 GAPS Legislative protection for holding persons in a secure facility without committee of person
36 Capabilities seldom black or white……context decision fluctuating but legally treated as such.
37 Re-look at Health Care consent and include care Facilities Admissions Act.

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38 Very Grey Zone. Capability fluctuate Need prevention NOT reaction.
39 Create a team decision making protocol that requires a collaborative review before a formal incapability assessment is conducted.
40 More openness to use CISL Program or create individualized funding.
41 Home support "rules" do not allow individualized plan.
42 GAP Nurse Practitioner support in GP Offices to assist with EDUC. – connections to services/supports.
43 Federal Compassionate Care program is only for immediate palliative, not for dementia caregivers
44 How to avoid using advance care planning tools as care rationing/cost cutting tool.
45 More types of short term respite, emergency, hourly, evening, weekend, single overnight.
46 Education in ER (? on-call CNS) DX of dementia increases risk of delirium – listen to the family, do not write off. The recent decline may be treatable.
47 Acute care seems to have difficulty recognizing dementia as an area for attention/ concern --------need for dementia friendly environment -------attitude change
48 Transitions throughout healthcare system arte poor e.g. home/facility, home/respite, home/acute info/timing/support needed
49 Elder Friendly hospital-Geriatric specialty areas.
50 Lack of (ongoing) assessment of caregiver's stresses. Even with supports it is still there.
51 Help individual make a representation agreement, if don't have one. This will strengthen their personal support.
52 Not utilizing RN's in LTC to full slope of practice as in the move towards utilizing LPN's.
53 Provide caregivers with the tools that will allow them to look after the resident's total needs. This results in less confusion to the residents.
54 Where do I go now? "No longer able to make decisions on own behalf", but needs are not "high" enough for "complex care" (giant gap)
55 More end of life care focus/education – not often a part of palliative care.
56 Staffing levels are too low in complex residential care – cannot implement best practices.
57 Good movement toward Eden alternatives in facility but still a long way to go.
58 Gap in understanding the transitions the individual/family experiences and how services should be designed to address these transitions.
59 Families have unreal expectations of care i.e. Insist resident is "properly dressed" when effort of re-buttoning sweater may cause stress.
60 Help educate. Families still 90% do not contact Alz Society}.
61 Relocation Trauma…..Detrimental to AD clients. Government access policies need to be reconsidered and aligned to prevent inter-facility moves. FA bed policies are not in "sync" with appropriately caring for these clients and their families. Let's look at this again please.
62 Need higher standards for educational requirements of recreation staff. These are important team members for meeting the needs of individuals with dementia. They can provide vital non-pharmacological interventions.
63 Concern about the use of tools such as advance care planning ostensibly with one objective (promote choice/autonomy) but with actual underlying policy driver of cut cost for high need persons (dementia)

64 Need to recognize….. "Bereavement" when a person is "dying by inches"
65 Caregiver becomes ill or dies while care giving due to caregiver overload.
66 Non-pharmacological resource: American Therapeutic Recreation Association Dementia Practice Guideline ATRA-TR.ORG
67 Marge Dempsey "Occult Grief in the caregiver of persons with dementia."
68 Experiential Knowledge – important, but limited lens. Need to augment knowledge with education.