



TYPE 1
diabetes
network

101 Solutions for Type 1 Diabetes

ISSUE 1: Access to specialist medical advice is very limited, especially in rural and regional areas

1. Establish in Australia a Centre for Excellence in Type 1 Diabetes
2. Develop evidence-based guidelines for treatment of Type 1 Diabetes in adults, including consumer resources (see also 9, below)
3. Extend access to specialists for rural and regional consumers through internet-based communications
4. Systematic review of current evidence and available consumer information about treatment of Type 1 Diabetes
5. Research, grow and disseminate the evidence base around key issues, including multiple autoimmune conditions, prevention, rare complications, exercise and diet
6. Disseminate current and new research about Type 1 Diabetes and evidence about treatment of Type 1 Diabetes to health professionals and consumers
7. Run short courses for medical professionals at a number of different levels to be accredited by the Centre for Excellence
8. Establish registers of providers (for example, psychologists, allied health professionals, GPs) who have completed specialist training in Type 1 Diabetes and make these registers available to consumers
9. Develop a comprehensive, evidence-based consumer information manual for adults with Type 1 Diabetes, combining medical information with practical advice from people with Type 1 diabetes
10. Create a web-based version of the same comprehensive manual
11. Create more endocrinology training places
12. Produce a video that uses humour to show what Type 1 Diabetes is; what people have to live with; how to recognise the symptoms, and how to get more support if you think you are at risk
13. Include a link to the Centre for Excellence's online portal on every computer the Federal Government is currently distributing to schoolchildren through the IT Revolution
14. Develop evidence-based community or family-based support programs
15. Develop a system to flag and manage psychological issues including diabetes burnout
16. Develop a group-based re-education program for young adults with Type 1 Diabetes
17. Embrace telemedicine for rural and regional consumer access to specialist medical advice
18. Develop and run parenting classes for parents of children with Type 1 Diabetes (or chronic disease)
19. Add diabetes educators to health call centres rolling out nationally
20. Disseminate widely advice about how to minimise or delay risk of Type 1 Diabetes in those known to be high risk
21. Develop evidence-based Psychological Guidelines for Diabetes (as being pursued by the Australasian Society for Psychological Research into Diabetes (ASPRID))
22. Develop a national protocol for treatment of hypoglycaemia in newborn babies of women with Type 1 – reviewing the appropriateness of using cow's milk.

ISSUE 2: Complexity of Type 1 Diabetes is neither well understood nor managed

23. Create a centralised, telephone-based 24-hour secondary consultation service for GPs and hospital doctors to access a team with expertise in Type 1 Diabetes
24. Routine and normalised consumer screening and review of mental health
25. Ensure a mental health professional is attached to or affiliated with every diabetes service
26. Normalise psychological referral immediately after diagnosis of Type 1 Diabetes to help the consumer cope with the idea of a condition that is going to be with them all day, every day
27. Increase awareness amongst people with Type 1 Diabetes about the services that do exist, such as online counselling and online communities
28. Ensure health psychology, especially inter-relationship between chronic disease and mental health, is incorporated into all psychology and mental health training courses
29. Ensure evidence of effective chronic disease self-management support (Wagner, Flinders, Stanford) is incorporated into services for people with Type 1 Diabetes
30. Recommendation of annual psychological consultation, and normalisation of use of mental health services
31. Patient-centred care evidence and principles adopted in Australia, and links built to work of experts such as the Picker Institute (www.pickereurope.org)
32. Ensure care coordination services are available for complex cases
33. Make simulation exercises available for parents, partners and others to learn something of the complexity of living with Type 1 Diabetes
34. Acknowledge that people with Type 1 Diabetes manage it 24 hours per day and medical input, in terms of time, is minimal
35. Include continuing education programs at hospital level, i.e. interns orientation, online education packages for residents, registrars, local doctors

ISSUE 3: Coping with long-term complications of Type 1 Diabetes is left to the individual with very limited support

36. Offer referral to a mental health professional to everyone diagnosed with a complication
37. Streamline service provision to ensure timely access to specialised medical advice for complicated or complex Type 1 Diabetes

ISSUE 4: Hospital admissions, planned and emergency, for people with Type 1 Diabetes are managed poorly when a diabetes team is not involved

38. Each consumer has a pre-determined Diabetes Plan which can be immediately enacted upon admission to hospital or in other emergencies
39. Ensure all planned admissions include pre-admission planning with a diabetes team for how the consumer's diabetes will be managed while they are in hospital
40. Create a comprehensive patient information resource for managing Type 1 Diabetes in hospital, including a care plan template
41. Develop an evidence-based clinical pathway for the hospital admission of someone with Type 1 Diabetes
42. Encourage every Type 1 to have a USB stick with all necessary medical information stored that can be accessed by ambulance, emergency departments and other hospital departments as required
43. Allow people with Type 1 Diabetes to manage their own diabetes while in hospital where they are able and willing
44. Ensure a credentialled diabetes educator is advised of all admissions for people with Type 1 Diabetes
45. Email or SMS someone on a hospital's diabetes team each morning listing all patients with Type 1 Diabetes in the hospital to enable flagging of those requiring extra care

46. Refer to endocrinologist or credentialled diabetes educator to develop a plan of care for management of Type 1 Diabetes in hospital, at pre-admission clinic if possible
47. Nurses to do assertiveness training
48. Make a national recommendation supporting that all people with Type 1 Diabetes have at least a phone consult with a diabetes team in a major centre regarding hospital admission and management
49. Local diabetes teams to lobby their administrations to adopt a policy about pre-admission clinic involvement in line with a national recommendation
50. Pursue funding for a project through the safety and quality initiatives at both state and federal levels to implement initiatives proposed to improve management of Type 1 Diabetes in hospitals
51. Investigate why major teaching hospitals have a Diabetes Educator or registrar on call 24 hours per day, but the resource is rarely utilised
52. Implement a new system for financial subsidy eligibility: link the NDSS card to a consumer's Medicare card, and use the existing tax threshold for the Medicare levy as a means test. If a consumer is required to pay the higher levy, the consumer is not entitled to an additional service and medication subsidy, but if the consumer is not required to pay the higher levy, the consumer is entitled to primary care services and medications related to diabetes at the concession rate
53. Investigate financial impacts of Type 1 Diabetes and co-morbidities and put in place a more flexible system for those on the cusp of qualifying for financial assistance
54. Develop a business case and benefit/cost analysis for a new system for financial subsidies
55. Educate people with Type 1 Diabetes about the need to maintain complications screening, (what and how). Possibly use a postcard campaign? Note that a mailing database already exists (NDSS)
56. Standard care becomes online/telephone-based support as required, complemented by in-person comprehensive annual review (and prescription provision) by experienced multi-disciplinary specialists in Type 1 Diabetes

ISSUE 5: System for the essential long-term monitoring of Type 1 Diabetes is inefficient and highly ineffective

52. Review the Medical Benefits Scheme (MBS) to better support chronic disease management
53. Broaden scope of professions that can initiate MBS care plans (to allow subsidised referrals to private psychologists, diabetes education, allied health) to include endocrinologists, diabetes nurse educators and other health professionals
54. Health professionals issue and accept indefinite referrals
55. Create centralised electronic records of all interventions, diagnoses and treatments, with patient primarily responsible for accessing and updating, and all health professionals contributing
56. Establish a D1 'Help Desk' – phone and email access to specialist advice as required
57. Create an automated system for complication screening recall and review

ISSUE 6: Adolescence and young adulthood is a critical stage with the worst outcomes

63. All major hospitals establish transition programs through formal partnerships between key providers: children's hospitals, adult hospitals, GPs, private endocrinology groups, pathology labs etc.
64. Remove financial disincentives to self-care for young adults
65. Extend Health Care Card eligibility automatically to all full-time students with a chronic medical condition
66. Normalise routine, comprehensive re-education of young adults with Type 1 Diabetes
67. Establish group-based re-education programs for young adults with Type 1 Diabetes
68. Review and support transition systems for children in regional and rural areas

- 69. Transition support must include linkages to phone lines and websites which are non-threatening, neutral spaces which are a gateway to in-person services
- 70. Not all young adults are transitioning; new diagnoses in this period are also common, and services need to cater to both scenarios
- 71. Develop individual programs for each person transitioning, which includes different options if one path doesn't work out, developed in consultation between a diabetes team and the young adult, and documented

ISSUE 7: Access to the best treatments and medical technologies is dependent on the ability to pay, not medical need

- 72. Treatment options must be based on clinical need rather than patient status or capacity to pay for unsubsidised options
- 73. Reduce the burden on diabetes nurse educators who are currently trying to fill the gaps created by lack of access to mental health services when not trained in this specialised area of support that is essential for all as a routine intervention
- 74. Create a national opt-in register of people with Type 1 Diabetes with bulletins issued as new treatments become available (also use to recruit participants for research and consumer feedback on policies)
- 75. Establish a 'bank' of insulin pumps to be lent to those who need them, with the pumps donated when users upgrade

ISSUE 8: Training teachers and schools about the basic needs of children with Type 1 Diabetes occurs haphazardly

- 76. Develop a national system for educating teachers and other school and childcare staff about common medical conditions including Type 1 Diabetes, customised to needs of each child
- 77. Add a 'health issues' module to courses for teachers and childcare workers, dealing with

what they will need to know about Type 1 Diabetes, asthma, epilepsy and other common conditions

- 78. Adapt new UK resources for Australia (<http://www.medicalconditionsatschool.org.uk>) and use the resources developed by the Chronic Conditions Alliance www.chronicillness.org.au/invisible to make available a simple support kit for parents and children to do presentations at schools (as is done for anaphylaxis)
- 79. Acknowledge that treatment options for a child's diabetes have a social and emotional impact, e.g. being withdrawn from the school environment to have injections at lunchtime
- 80. Parents and children should be presented with a range of treatment options and the evidence for their effectiveness, from pumps to twice daily injections, and decisions about treatment made collaboratively for the most suitable considering a range of medical and psychosocial parameters
- 81. School canteens adapt – to a degree – their range of food in order to cater for the needs of children with Type 1 Diabetes
- 82. Enable children to distribute practical information about Type 1 Diabetes to their classmates, teachers, friends and families, for example, by providing them with a specially prepared pamphlet produced by Diabetes Australia
- 83. Ensure education is focused on all staff in the school, not just the classroom teacher of a child with Type 1 Diabetes, for example, the librarian, the physical education instructor, the coach, the music teacher, any fill-in teacher, any playground duty teacher

ISSUE 9: Peer learning opportunities for people with Type 1 Diabetes are essential but very limited and difficult to access

- 84. Standard care to include facilitated introduction to others in similar situation, and those avenues developed or supported
- 85. Revival and replication around Australia of the buddy program established in ACT

86. Develop and encourage online communities
87. Create a telephone peer support line
88. Organise camps or weekends away for adults with Type 1 Diabetes
89. Invite older adults with Type 1 Diabetes to children's camps as mentors
90. Diabetes Australia to help in developing support groups for children and their families in rural and regional areas by running initial meetings where interested families would be invited to take over
91. Wider advertising of websites that already fulfil a major role in providing peer support, such as the Reality Check website
92. Investigate development of more structured online support groups
93. Celebrate and publicise successful people with Type 1 Diabetes from different walks of life as potential role models

ISSUE 10: Leadership and advocacy for Type 1 Diabetes needs to be strengthened urgently

94. Replicate the 'Cancer Voices' program for Type 1 Diabetes
95. Increase the involvement of people with Type 1 Diabetes in policy and health service development
96. Establish a Clearinghouse for activity and good practice in Type 1 Diabetes – link with raising the profile and developing partnerships
97. Encourage students to do theses on innovative models suggested here to increase evidence of their effectiveness (or otherwise)
98. Encourage people with Type 1 Diabetes to directly express thanks when media outlets portray the condition accurately
99. Wider promotion of the Medtronic & JDRF Media Awards for reporting of Type 1 Diabetes
100. What is Diabetes Australia doing for people with Type 1 Diabetes?
101. Obtain professional advice about how to develop messages for the public/media about Type 1 Diabetes which balance the conflicting issues of victims, blame, 'no big deal'

This document was developed by The Type 1 Diabetes Opinion Leaders Group through their work to develop a Statement of Issues effecting Australians with Type 1 Diabetes.

Health professional bodies, non-government organisations, industry groups and consumer groups were represented alongside people with Type 1 Diabetes and parents of children with Type 1 Diabetes. Representatives of other key groups were also included: private endocrinology, psychology and counselling, adolescent diabetes services, tertiary hospitals, regional services, health promotion, general practice, pregnant women and rural families.

For the Statement of Issues and more information, visit:

www.d1.org.au/issues

August 2008