

# Improving Health Literacy for People with Diabetes

March 2015

This document was developed by Australian Diabetes Educators Association (ADEA) with funding from the National Diabetes Services Scheme (NDSS).

**The Commonwealth is not responsible for any recommendations, views, ideas or techniques expressed in this publication.**

Disclaimer: The medical information provided in this document is of a general nature and cannot substitute for professional medical advice, diagnosis, or treatment. Please seek medical advice from your healthcare professionals with any questions you may have regarding a medical condition.

## Purpose

The purpose of this document is to provide practice recommendations to Diabetes Educators and other health professionals to better support health literacy for people with diabetes, their families and carers. Developing health literacy in diabetes management will be achieved through genuine, inclusive engagement of clients, their families and carers, all levels of health services as well as the wider community.

It is acknowledged that the environment in which Diabetes Educators/Credentialed Diabetes Educators (DE/CDEs) and other health professionals work is not always supportive of health literacy for people with diabetes, their families and carers. While health services often state they are committed to partnering with consumers and supporting health literacy, this commitment is not always integrated into service mission statements, values and policies.<sup>1</sup> This document encourages DEs/CDEs and other health professionals to use culturally and socially inclusive work practices to enable their clients to develop and apply health literacy. It also encourages all health professionals and their health service management to advocate for health organisations to be health literate for the benefit of people with diabetes, their families and carers.

## Health literacy

*Approximately 60 per cent of Australians have poor health literacy and are not able to effectively exercise their 'choice' or 'voice' when it comes to making health care decisions.<sup>2</sup>*

A health literate organisation or practitioner recognises the individual skills and abilities of consumers and the demands placed on them by the health system. An individual's level of health literacy will influence both their decisions and their actions. This makes improving a health system's health literacy a priority for all health practitioners, managers and policy makers.

This document uses the definition of health literacy adopted by the Australian Commission on Safety and Quality in Health Care (ACSQHC):

*Individual health literacy is the knowledge, motivation, skills and capacity of a person to access, understand, appraise and apply information to make effective decisions about health and health care, and make appropriate decisions. The health literacy environment is the infrastructure, policies, processes, materials, people and relationships that have an impact on the way in which people access, understand, appraise and apply health-related information and services.<sup>3</sup>*

The concept of health literacy is not new in Australian health policy. The term 'health literacy' emerged in the 1970s<sup>4</sup> and by the 1990s it was appearing in academic literature.<sup>5</sup> Health literacy was included in Australia's first set of national health goals and targets in 1993<sup>6</sup> and in 2007, the National Health and Hospitals Reform Commission identified health literacy as a key factor in stronger consumer engagement.<sup>7</sup>

Health literacy is fundamental to support effective self-management education. Self-management education is a key component of care in all chronic conditions.

Health literacy is not simply a specific use of general literacy: the two are linked but not correlated.<sup>8</sup> Low general literacy and low health literacy are both associated with vulnerability and inequity in health care.<sup>9</sup>

Health literacy is enhanced through health literate environments. The Institute of Medicine<sup>10</sup> has identified 10 attributes of a health literate organisation<sup>11</sup> which are cited by ACSQHC and widely applied internationally.

These encompass:

- Leadership
- Integration of health literacy into planning, evaluation measures, patient safety and quality improvement
- Workforce development
- Consumer engagement
- Inclusion (the whole community rather than a targeted approach)
- Using health literacy strategies in interpersonal communication
- Provision of easy access to health information and services with navigation assistance
- Message and information content
- High risk management
- Informed consent and financial consent.

**It's not about diabetes, it's about us. We're not our diagnosis. We don't want to be patronised, we don't need to feel guilty and we don't want a scorecard for diabetes control – we need recognition, information and support for the hard work we do every day to keep well.**

**Consumer - Type 1 Voice**

ACSQHC has identified health literacy as a priority through a number of national policies including:

- Australian Safety and Quality Framework for Health Care, in which health literacy is a key action area<sup>12</sup>
- Australian Safety and Quality Goals for Health Care, which includes Partnering with Consumers as a goal and becoming a health literate organisation as a core outcome (Outcome 3.03)<sup>13</sup>
- The National Safety and Quality Health Service Standards, which require health service organisations to provide information that meets the needs of consumers.<sup>14</sup>

There are different aims and approaches to measuring health literacy. Tools are available and being developed to measure and assess individual knowledge, capabilities and skills, as well as the health literacy environment – and the dynamic relationship between them.

## Development of this document

This document was developed to assist DEs/CDEs and other health professionals to prioritise and enable health literacy for people with diabetes, their families and carers and to advocate for health services that support health literacy.

This document was drafted by a consultant and informed by a rapid review of the literature.<sup>15</sup> Consultations were held with consumers, consumer health organisations and ADEA members.

## Overview

Safety, quality and shared decision making with clients is enhanced when people with diabetes are health literate and the health service environment supports and facilitates health literacy.

## Principles

- People with diabetes are the first and most significant day-to-day managers of their diabetes and their lives; their decisions and actions are fundamental to the safety, quality and effectiveness of their diabetes care
- How and why people with diabetes make diabetes care decisions are influenced by their knowledge, values, beliefs, preferences, skills and capacities and by the environments in which they make and enact those decisions
- Health literacy, including health numeracy, contributes to client safety, particularly in terms of medication self-management and safety;<sup>16, 17</sup> better health-related quality of life and lower levels of anxiety and depression;<sup>18</sup> and fewer adverse health outcomes<sup>19</sup>
- Health literacy reduces health costs at an individual and systemic level<sup>20</sup> and lessens the multiple health disadvantage experienced by already vulnerable groups<sup>21</sup>
- People who do not know about or understand treatment options cannot give informed consent
- People who understand and agree with health care and treatment recommendations are better equipped to enact them
- Health literacy is not achieved by health professionals simply conveying information to clients about diabetes: it is a shared process with clients, their families and carers and the community to ensure people with diabetes are supported to self-manage and achieve their goals
- Diabetes information and decision-making tools need to be developed with clients, and the community, and used in shared decision-making, to ensure they are easy to access, understand, choose and use

- A health workforce that is health literate in relation to diabetes management makes it easier for people with diabetes when they are seeking assistance with routine and emergency health care needs not related to their diabetes
- A community that is health literate in relation to diabetes management makes it easier for people with diabetes to achieve the everyday self-management tasks that keep them well
- Clients should not be expected to navigate complex health services unassisted: services should be co-designed, managed and monitored to maximise client ease of access<sup>22, 23</sup>
- Health services should provide universal health literacy support. All clients, their families and carers, irrespective of their general literacy, should be supported to understand diabetes, care options, how to access diabetes services and how to navigate the system to get the greatest benefit for the least cost
- Services that are difficult to navigate, understand and use contribute to discrimination, in particular to vulnerable clients
- Well-designed health services can make it easier for all clients to understand when and how to access primary care and community services to manage and prevent problems, rather than rely on acute care services
- Communities are stronger and people living with diabetes are safer when there is community education about diabetes, when consumers participate in health service co-design, co-delivery and co-evaluation<sup>24</sup> and equity is addressed through a greater understanding of the social determinants of health.

**We don't need ten years' information all at once – we need simple, clear, relevant information, when we need it.**

**Consumer – Type 1 Voice**

## Recommendations for practice

DE/CDEs and health professionals support health literacy through:

1. Provision of comprehensive evidence-based diabetes information
2. Shared decision making in all communications and documentation
3. Promotion of health literate services and communities
4. Evidence-based education programs. Recommendations follow for each of these areas of practice.

### **1. Provision of comprehensive evidence-based general diabetes care information is universally available in a range of accessible formats.**

Practitioners should:

- Ensure general diabetes care information is widely available and encompasses diagnosis; processes and likely outcomes of tests and treatments; safe and effective use of medicines; self-management; maximising quality of life and wellbeing; and health treatment and service pathways with details of access, costs, payment and relevant subsidised schemes. This responsibility is shared with all health professionals.
- Ensure clinical information is verified and cite the professionals or group that have confirmed the information's accuracy, currency and relevance
- Ensure consistency with the Diabetes Australia Position Statement: *A new language for diabetes*<sup>25</sup>
- Ensure the content, format and means of access to information are consumer tested for relevance, accessibility and ease of understanding by all client groups
- Use simple language and ensure graphics add meaning to the message – for all clients in written and verbal communication
- Locate and provide access to information in formats relevant to all clients, their families and carers, for example in other written, spoken and signed languages; visual descriptors as well as the written word; hard copy, online and audio explanations; face-to-face explanations; and interactive and social media
- Assess clients' health literacy using an agreed and available tool
- Secure assistance to access translation services and disability, communication and social support
- Encourage clients to critically appraise information for personal relevance and check they have understood what it means for them by using methods such as “teach back”

Don't assume what I need to know about my child or my grandchild's diabetes management based on how well educated you think I am – everyone needs the 'silly questions' answered – often more than once.

Consumer - Type 1 Voice

## **2. All communication and documentation encourages informed, shared decision making.**

Practitioners should:

- Encourage shared decision making and goal setting using clearly documented processes, for example in client diaries, community care plans and medical records
- Actively seek and use client reports about self-management, wellbeing, priorities and concerns to provide needs-based information to each client, their families and to carers as requested, and to check the information is understood and accepted
- Answer client questions in a respectful and culturally inclusive manner that contributes to informed decision making and goal setting
- Suggest clients think about and record questions they can ask health professionals so they can be prepared for future consultations
- Provide follow-up written information or personal contact to aid recall and understanding
- Use face to face consultations to further explain, clarify and support the client's understanding of information provided to, or accessed by, the client. This consultation includes health service options and how to navigate and use the health system for least cost and greatest benefit
- Ensure clients have easy access to their health records consistent with the National Privacy Principles.<sup>26</sup>

## **3. Health literate services and communities are a priority**

Practitioners should:

- Advocate for diabetes consumer engagement in service design, delivery and monitoring and evaluation, to help create services that are health literate in relation to diabetes management
- Communicate best practice care information and the support needs of their client group to local primary, secondary and tertiary health care services

- Customise and disseminate general diabetes information widely in the community, to create a diabetes literate Australia.

#### **4. Diabetes education programs are evidence-based**

Practitioners should implement evidence-based practice and contribute to practice-based evidence.

It's not just the person with diabetes who needs information and decision making support – carers, friends, family, employers, the wider community need information. And so do health professionals – many of us have had to argue with doctors in hospitals about our care – they even get type 1 and type 2 confused and they try to change our care plans and start from scratch.

Consumer - Type 1 Voice

Effective diabetes education occurs when there is a respectful exchange of information and shared decision making between clinicians, and between clinicians and clients. Best practice health literacy in diabetes management applies best evidence through the process of partnering with clients in a supportive health services environment.

Practitioners should make professional judgments, within their scope of practice, regarding the application of the research evidence to their practice context. Current best quality evidence, as assessed in an international systematic literature review undertaken for ADEA, identifies the following elements of evidence-based practice in diabetes education. Practitioners should take this evidence into account when making professional judgements about their practice:

- Experienced or (certified nurse educator)<sup>27</sup> Experienced/Credentialed Diabetes Educator in the Australian context are prepared to engage in ongoing professional development<sup>28</sup>
- Take a multidisciplinary primary health care approach<sup>29</sup>
- Provide structured programmes to *achieve individual's glycaemic control with an acceptable amount of hypoglycaemia*.<sup>30,31</sup> This recommendation should be considered in the context of emerging evidence on the value of individualisation of care and meeting the needs of young children and frail older people.
- Include face-to-face interaction and a cognitive reframing teaching method
- Target and measure self-management and psychosocial as well as physiological outcomes using relevant valid assessment tools<sup>32</sup>
- Develop standardised diabetes education information that is customised and accessible to all patients<sup>33</sup>

- Tailor the program to the culture<sup>34</sup> and needs<sup>35</sup> of the people with whom you are working including cognitive capacity<sup>36</sup> and health literacy
- Assess patient understanding by using tell back or teach back techniques<sup>37</sup>
- Consider using peer education approaches if they are suitable to the group<sup>38</sup>
- Provide at least four multicomponent<sup>39</sup> sessions, encompassing didactic and interactive elements and including problem solving<sup>40-44</sup>
- Include individual and/or group counselling,<sup>45</sup> *using facilitators such as pharmacists, nurse educators (experienced/Credentialed Diabetes Educator in the Australian context) or community health workers<sup>46</sup>* and use interactive multimedia programs<sup>47</sup>
- Use the internet and technology for ongoing self-management support<sup>48</sup> and take into account language, age, gender, ethnicity, reading ability, health literacy level (including technology related literacy) and specific goals or needs<sup>49</sup>
- Use scripted and unscripted telephone coaching, particularly with vulnerable groups<sup>50,51</sup>
- Use plain language, limit the number of concepts and health information prescriptions that include links or recommendation to an appropriate website and/or referral to a health librarian (where one exists)<sup>52</sup>
- Ensure the planning, design and implementation of assistive technology is user- centred and takes account of the social context in which the technology is applied<sup>53</sup>
- Use multiple dimensions to evaluate self-management effectiveness, including motivation for self-management, long-term adherence, cost, adoption, satisfaction and outcomes.<sup>54</sup> Evaluation must include relevance to the individual, community and sociocultural context.

## References

- <sup>1</sup> Australian Commission on Safety and Quality in Health Care (ACSQHC). Health Literacy Stocktake: Consultation Report. 1974. ACSQHC
- <sup>2</sup> ACSQHC. Available from: <http://www.safetyandquality.gov.au/our-work/patient-and-consumer-centred-care/health-literacy/>. Accessed 30 March 2014
- <sup>3</sup> Australian Commission on Safety and Quality in Health Care (ACSQHC). Consultation Paper, Consumers, The health system and health literacy: Taking action to improve safety and quality. 2013 – revised definition as advised by ACSQHC: email 24 March 2014
- <sup>4</sup> Simonds S. *Health education as social policy*. Health Education Monograph. 1974; 2:1-25
- <sup>5</sup> Pleasant A., *Health Literacy Around the World: Part 1*. Health Literacy Efforts Outside of the United States. 2012; 12(80)
- <sup>6</sup> Nutbeam D, Wise M, Bauman A, Harris E, et al. *Goals and Targets for Australia's Health in the Year 2000 and Beyond*. Commonwealth of Australia. 1993
- <sup>7</sup> National Health and Hospitals Reform Commission (NHHRC). *A Healthier Future for All Australians: Final Report of the National Health and Hospitals Reform Commission*. NHHRC. 2009
- <sup>8</sup> Australian Bureau of Statistics: Health Literacy. Australian Bureau of Statistics. 2008.
- <sup>9</sup> Berkman N, Sheridan S, Donahue K, Halpern D et al., *Health Literacy Interventions and outcomes: An Updated Systematic Review*. Evidence Report/Technology Assessment, Agency for Healthcare Research and Quality. 2011
- <sup>10</sup> <http://www.iom.edu/About-IOM.aspx>
- <sup>11</sup> Brach C, Keller D, Hernandez I, Baur C et al. *The attributes of health literate health care organizations*. Washington DC. Institute of Medicine. 2012
- <sup>12</sup> Australian Safety and Quality Framework for Health Care. <http://www.safetyandquality.gov.au/national-priorities/australian-safety-and-quality-framework-for-health-care/>
- <sup>13</sup> Australian Safety and Quality Goals for Health Care Partnering with Consumers: Action Guide, <http://www.safetyandquality.gov.au/national-priorities/goals/australian-safety-and-quality-goals-for-health-care-overview-and-action-guides>. ACSQHC. 2012
- <sup>14</sup> National Safety and Quality Health Service Standards. <http://www.safetyandquality.gov.au/our-work/accreditation/nsqhss>. ACSQHC. 2011
- <sup>15</sup> Lizarondo L, Wiles L, Australian Diabetes Educators Association. *Rapid Review of Literature for Health Literacy in People with Diabetes*, International Centre for Allied Health Evidence, University of South Australia, February 2014 (Unpublished)
- <sup>16</sup> Davis T, Wolf M, Bass I, Thompson J et al. *Literacy and misunderstanding prescription drug labels*. *Annals of Internal Medicine*. 2006; 145(12): 887-894
- <sup>17</sup> Davis T, Wolf M, Bass P, Middlebrooks M et al., *Low literacy impairs comprehension of prescription drug warning labels*. *Journal of General Internal Medicine*. 2006; 21(8): 847-851
- <sup>18</sup> Husson O, Mols F, Van de Poll-Franse LV. *The relation between information provision and health-related quality of life, anxiety and depression among cancer survivors: A systemic review*. *Annals of Oncology*. 2011; 22: 761-772
- <sup>19</sup> DeWalt D, Berkman N, Sheridan S, Lohr K et al. *Literacy and health outcomes: Systematic review of the literature*. *Journal of General Internal Medicine* 2004; 19: 1228-1239
- <sup>20</sup> Eichler K, Wieser S, Brugger U. *The costs of limited health literacy: A systematic review*. *International Journal of Public Health*. 2009; 54:313-324
- <sup>21</sup> Ethnic Communities Council of Victoria (ECCV). *An Investment Not An Expense: Enhancing health literacy in culturally and linguistically diverse communities*. ECCV. 2012
- <sup>22</sup> Paasche-Orlow M, Wolf M. *The causal pathways linking health literacy to health outcomes*. *American Journal of Health Behaviour*. 2007; 31(Suppl 1): S19-S26
- <sup>23</sup> Nutbeam D. *The evolving concept of health literacy*. *Social Science and Medicine* 2008; 67 (12):2072-2078
- <sup>24</sup> Kings Fund. Experience-based co-design tool kit. Available at: <http://www.kingsfund.org.uk/search/site/codesign>, Kings Fund. 2013
- <sup>25</sup> Diabetes Australia. Position Statement: A new language for diabetes – Improving communications with and about people with diabetes. 2011
- <sup>26</sup> Office of the Australian Information Commissioner, Privacy Act 1988, Schedule 3

- <sup>27</sup> Walker R, Smalls B, Bonilha H, Campbell J. *Ethnicity & Disease*. 2013; 23(4): 401-8
- <sup>28</sup> Lou, Q; Wu, L, Dai, X, Cao, M, Ruan, Y. *Diabetes education in mainland China—A systematic review of the literature*. Patient Education & Counseling. 2011; 85(3): 336-347
- <sup>29</sup> Hunt C, Grant J, Appel J. [An Integrative Review of Community Health Advisors in Type 2 Diabetes](#). Journal of Community Health. 2011; 36(5): 883-893
- <sup>30</sup> Leelarathna L, Guzder R, Muralidhara K, Evans M. *Diabetes: glycaemic control in type 1*. Clinical Evidence. 2011
- <sup>31</sup> Duke S, Colagiuri S, Colagiuri R. *Individual patient education for people with type 2 diabetes mellitus*. Cochrane database of systematic reviews. 2009
- <sup>32</sup> Albano M, Crozet C, D'Ivernois J. *Analysis of the 2004-2007 literature on therapeutic patient education in diabetes: Results and trends*. Acta Diabetologica. 2008; 45(4): 211-219
- <sup>33</sup> Lou Q, Wu L, Dai X Cao M, R Y. *Diabetes education in mainland China—A systematic review of the literature*. Patient Education & Counseling. 2011; 85(3): 336-347
- <sup>34</sup> Walker R, Smalls B, Bonilha H, Campbell J et al. *Behavioral interventions to improve glycemic control in African Americans with type 2 diabetes: a systematic review*. Ethnicity & Disease. 2013; 23(4): 401-8
- <sup>35</sup> Hawthorne K, Robles Y, Cannings-John R, Edwards, A. [Realist review to understand the efficacy of culturally appropriate diabetes education programmes](#). Diabetic Medicine. 2010; 27(6): 613-623
- <sup>36</sup> Albano M, Crozet C, D'Ivernois J. *Analysis of the 2004-2007 literature on therapeutic patient education in diabetes: Results and trends*. Acta Diabetologica. 2008; 45(4): 211-219
- <sup>37</sup> Boren S, Fitzner K, Panhalkar P, Specker J. *Clinical trials of interactive computerized patient education: Implications for family practice*. The Diabetes Educator. 2009; 35(1): 72-96
- <sup>38</sup> Dale J, Williams S, Bowyer V. *What is the effect of peer support on diabetes outcomes in adults? A systematic review*. Diabetic Medicine. 2012;29(11): 1361-1377
- <sup>39</sup> Loveman E, Frampton G, Clegg A. *The clinical effectiveness of diabetes education models for Type 2 diabetes: a systematic review*. Health technology assessment. 2008;12(9): 1-116
- <sup>40</sup> Fan L, Sidani S. *Effectiveness of diabetes self-management education intervention elements: A meta-analysis*. Canadian Journal of Diabetes. 2009; 33(1): 18-26
- <sup>41</sup> Fitzpatrick S, Schumann K, Hill-Briggs F. *Problem solving interventions for diabetes self-management and control: A systematic review of the literature*. Diabetes Research and Clinical Practice. 2013; 100(2): 145-161
- <sup>42</sup> Williams J, Walker R, Smalls B, Campbell J, et al. *Effective interventions to improve medication adherence in Type 2 diabetes: A systematic review*. Diabetes Management. 2014; 4(1): 29-48
- <sup>43</sup> Walker R, Smalls B, Bonilha H, Campbell J. *Behavioral interventions to improve glycemic control in African Americans with type 2 diabetes: a systematic review*. Ethnicity & Disease. 2013; 23(4): 401-8
- <sup>44</sup> Jayasekara R, Munn Z, Lockwood C. *Effect of educational components and strategies associated with insulin pump therapy: a systematic review*. International Journal of Evidence-Based Healthcare. 2011; 9(4): 346-361
- <sup>45</sup> Sarkisian C, Brown A, Norris K, Wintz R, et al. *A systematic review of diabetes self-care interventions for older, African American, or Latino adults*. The Diabetes Educator. 2003; 29(3): 467-479
- <sup>46</sup> Williams J, Walker R, Smalls B, Campbell J, et al. *Effective interventions to improve medication adherence in Type 2 diabetes: A systematic review*. Diabetes Management. 2014; 4(1): 29-48
- <sup>47</sup> Boren S, Fitzner K, Panhalkar P, Specker J. [Costs and benefits associated with diabetes education: A review of the literature](#). The Diabetes Educator. 2009; 35(1): 72-96
- <sup>48</sup> Williams J, Walker R, Smalls B, Campbell J, et al. *Effective interventions to improve medication adherence in Type 2 diabetes: A systematic review*. Diabetes Management. 2014; 4(1): 29-48
- <sup>49</sup> Boren S, Fitzner K, Panhalkar P, Specker J. [Costs and benefits associated with diabetes education: A review of the literature](#). The Diabetes Educator. 2009; 35(1): 72-96
- <sup>50</sup> Dennis S, Harris M, Lloyd J, Powell D, et al. *Do people with existing chronic conditions benefit from telephone coaching? A rapid review*. Australian Health Review. 2013; 37(3): 381-388.
- <sup>51</sup> Boren S, Fitzner K, Panhalkar P, Specker J. [Costs and benefits associated with diabetes education: A review of the literature](#). The Diabetes Educator. 2009; 35(1): 72-96
- <sup>52</sup> *ibid*.
- <sup>53</sup> El-Gayar O, Timsina P, Nawar N, Eid W. *A systematic review of IT for diabetes self-management: Are we there yet?* International Journal of Medical Informatics. 2013; 82(8): 637-652
- <sup>54</sup> *ibid*