

# 8. References



1. Smart J. Needs assessment: Families and Children Expert Panel practice resource. Melbourne: Australian Institute of Family Studies, 2019.
2. Pattoni L. Strength-based approaches for working with individuals. Insight 16. Glasgow: Institute for Research and Innovation in Social Services (Iriss), 1 May 2012. <<https://www.iriss.org.uk/resources/insights/strengths-based-approaches-working-individuals> Accessed 16 March 2020>
3. Jones P. Living with haemophilia, 5th ed. Oxford:Oxford University Press, 2002.
4. National Blood Authority. Australian Bleeding Disorders Registry Annual Report 2017-18. Canberra: NBA, 2018.
5. World Federation of Haemophilia. Acquired hemophilia. Montreal: WFH, 2012.
6. Benson G, Auerswald G, Dolan G, et al. Diagnosis and care of patients with mild haemophilia: practical recommendations for clinical management. *Blood Transfusion* 2018 Nov;16(6):535-544.
7. Haemophilia Foundation Australia. Women and bleeding disorders project report. Unpublished report, Melbourne, 2002.
8. Australian Haemophilia Centre Directors' Organisation. Guidelines for the management of haemophilia in Australia. Canberra: National Blood Authority, 2016.
9. National Blood Authority; Australian Haemophilia Centre Directors' Organisation. Evidence-based clinical practice guidelines for the use of recombinant and plasma-derived FVIII and FIX products. Australian Health Ministers' Advisory Council: Canberra, 2006.
10. World Federation of Hemophilia. von Willebrand Disease and Rare Bleeding Disorders Committee. Rare clotting factor deficiencies. May 2012. < <https://elearning.wfh.org/elearning-centres/rare-clotting-factor-deficiencies> Accessed 16 March 2020 >
11. World Federation of Hemophilia. Guidelines for the management of hemophilia. 2nd edn. WFH: Montreal, 2012.
12. Plug I, van der Bom JG, Peters M, et al. Mortality and causes of death in patients with hemophilia, 1992–2001: a prospective cohort study. *Journal of Thrombosis and Haemostasis* 2006; 4: 510–6.
13. Darby SC, Kan SW, Spooner RJ, et al. Mortality rates, life expectancy, and causes of death in people with hemophilia A or B in the United Kingdom who were not infected with HIV. *Blood*. 2007;110(3):815-25.
14. Mazepa MA, Monahan PE, Baker JR, et al. Men with severe hemophilia in the United States: birth cohort analysis of a large national database. *Blood*. 2016;127(24):3073-81.
15. Kasper CK. Hemophilia: a cautionary status report. *Blood*. 2016; 127(24):2949-50.
16. Oldenburg J, Dolan G, Lemm G. Haemophilia care then, now and in the future. *Haemophilia* 2009;15(Suppl. 1):2-7.
17. Angelini D, Sood SL. Managing older patients with hemophilia. *Hematology: American Society of Hematology Education Program*. 2015; 2015(1):41-7.
18. Canaro M, Goranova-Marinova V, Berntorp E. The ageing patient with haemophilia. *European Journal of Haematology* 2015; 94 (Suppl. 77): 17-22.
19. Skinner MW, Nugent D, Wilton P, et al. Achieving the unimaginable: health equity in haemophilia. *Haemophilia* 2020;1:17-24.
20. Haemophilia Foundation Australia. "A double whammy": living with a bleeding disorder and hepatitis C. Melbourne: HFA, 2007.
21. Ekert, H, Ekert,NL, Street, AM et al. Haemophilia A management in Victorian, New South Wales and South Australian haemophilia centres *MJA* 1995;162:569-571.
22. Northcott, MJ, Ong, WL, Walsh, M, et al. Prevalence of transfusion-acquired hepatitis C in an Australian bleeding disorders population. *Haemophilia* 2013;19(6):847-52.
23. Dolan G, Hermans C, Klamroth R, et al. Challenges and controversies in haemophilia care in adulthood. *Haemophilia* 2009;15(Suppl. 1):20-27.
24. Dolan G. The challenge of an ageing haemophilic population. *Haemophilia* 2010;16 (Suppl. 5): 11–16.
25. Hermans C, de Moerloose P, Dolan G. Clinical management of older persons with haemophilia. *Crit Rev Oncol Hematol* 2014; 89(2): 197-206.
26. Konkle BA, Kessler C, Aledort L, et al. Emerging clinical concerns in the ageing haemophilia patient. *Haemophilia* 2009; 15(6): 1197-209.
27. Mauser-Bunschoten EP, Fransen Van De Putte DE, Schutgens RE. Co-morbidity in the ageing haemophilia patient: the down side of increased life expectancy. *Haemophilia* 2009; 15(4): 853-63.

28. Smith N, Bartholomew C, Jackson S. Issues in the ageing individual with haemophilia and other inherited bleeding disorders: understanding and responding to the patients' perspective. *Haemophilia* 2014; 20(1): e1-6.
29. World Health Organization. Proposed working definition of an older person in Africa for the MDS Project. 2002. <<https://www.who.int/healthinfo/survey/ageingdefnolder/en/>> Accessed 16 March 2020.>
30. Australian Government. My Aged Care. Types of care. <<https://www.myagedcare.gov.au/types-care>> Accessed 16 March 2020 >
31. Australian Government. Services Australia. Centrelink. Age Pension – who can get it? <<https://www.servicesaustralia.gov.au/individuals/services/centrelink/age-pension/who-can-get-it>> Accessed 16 March 2020>.
32. World Health Organization. World report on ageing and health. Geneva: WHO, 2015.
33. Australian Government. Productivity Commission. Shifting the dial: 5 year productivity review. Report No. 84. Productivity Commission: Canberra, 2017.
34. World Health Organization. WHOQOL: Measuring Quality of Life. <<https://www.who.int/healthinfo/survey/whoqol-qualityoflife/en/index4.html>> Accessed 15 May 2020 >
35. Australian Government. Productivity Commission. Integrated Care. Shifting the Dial: 5 year Productivity Review, Supporting Paper No. 5. Productivity Commission: Canberra, 2017.
36. Australian Commission on Safety and Quality in Health Care. Health literacy: Taking action to improve safety and quality. ACSQHC: Sydney, 2014.
37. Felton BJ, Revenson TA. Coping with chronic illness: a study of illness controllability and the influence of coping strategies on psychological adjustment. *Journal of Consulting and Clinical Psychology* 1984; 52(3): 343-353.
38. Weitz R. Uncertainty and the lives of people with AIDS. *Journal of Health and Social Behavior*. 1989; 30(3): 270-281.
39. Skinner MW, Chai-Adisaksopha C, Curtis R, et al. The Patient Reported Outcomes, Burdens and Experiences (PROBE) Project: development and evaluation of a questionnaire assessing patient reported outcomes in people with haemophilia. *Pilot and Feasibility Studies*. 2018; 4:58.
40. Chai-Adisaksopha C, Skinner MW, Curtis R, et al. Test-retest properties of the Patient Reported Outcomes, Burdens and Experiences (PROBE) questionnaire and its constituent domains. *Haemophilia*. 2019;25:75–83.
41. Germini F, O'Callaghan S, Chai-Adisaksopha C, et al. Association between aging and health status in persons living with hemophilia and controls without a bleeding disorder - Insights from the PROBE Study. [Abstract PB1012]. Abstract accepted for ISTH 2020 Virtual Congress, 12-14 July 2020.
42. Jones PK, Ratnoff OD. The changing prognosis of classic hemophilia (factor VIII "deficiency"). *Annals of Internal Medicine*. 1991;114(8):641-648.
43. Australian Red Cross Blood Service. Submission prepared for the Senate Community Affairs References Committee Inquiry Into Hepatitis C And Blood Supply In Australia. ARCBS: Sydney, December 2003.
44. Victoria. Department of Health. Vaccine history timeline. <<https://www2.health.vic.gov.au/public-health/immunisation/immunisation-schedule-vaccine-eligibility-criteria/vaccine-history-timeline>> accessed 3 March 2020>
45. Vidovic N, Heilmeier A, Goldmann G, et al. Demographic data from 1970–2006 of the Haemophilia Center Bonn. *Haemophilia* 2008;14(Suppl.2):121-158. Abstract 24 PO 23.
46. Arnold DM, Julian JA, Walker IR. Mortality rates and causes of death among all HIV-positive individuals with hemophilia in Canada over 21 years of follow-up. *Blood*. 2006;108:460-464.
47. Leslie DE, Rann S, Nicholson S, et al. Prevalence of hepatitis C antibodies in patients with clotting disorders in Victoria. *Medical Journal of Australia* 1992;156:789-792.
48. Polizotto M, Mudge L, Walsh M, et al. Blood, sweat and tears: clinical and psychosocial outcomes over 25 years in patients with haemophilia infected with HIV [abstract]. 14th Australian & New Zealand Haemophilia Conference, Canberra, 4-7 October 2007.
49. Harris TG, Rabkin M, El-Sadr WM. Achieving the fourth 90: healthy aging for people living with HIV. *AIDS* 2018, 32:1563–1569.
50. Parikh S, Tran H, McRae S. Uptake of subsidised hepatitis C direct acting antiviral treatment among patients with bleeding disorders in Australia [abstract]. *Haemophilia* 2018;24(Suppl. 5):1-218.
51. Hepatitis C Virus Infection Consensus Statement Working Group. Australian recommendations for the management of hepatitis C virus infection: a consensus statement. Melbourne: Gastroenterological Society of Australia, September 2018.
52. Iorio A, Stonebraker JS, Chambost H, et al. Establishing the prevalence and prevalence at birth of hemophilia in males: a meta-analytic approach using national registries. *Annals of Internal Medicine* 2019;171(8):540-546.

53. Harrison C, Sacculo G, Makris M. Haemophilia of the third age. *Haemophilia* 2018;24:15-16.
54. Rickard KA, Batey RG, Dority P et al. Hepatitis and haemophilia therapy in Australia. *Lancet* 1982;2(8290):146-8.
55. Roberts A. Recombinant factor VIII and IX for haemophilia – success at last; discrimination to end. *National Haemophilia* Oct 2004;148:1-3.
56. Ross J. Major treatment breakthrough. *National Haemophilia* Jul 1995;95:1.
57. Ross J. Time to say thank you: factor VIII update. *National Haemophilia* Sep 1995;97:1-2.
58. O’Hara J, Sima CS, Frimpter J, et al. Long-term outcomes from prophylactic or episodic treatment of haemophilia A: a systematic review. *Haemophilia* 2018;24:e301-e311.
59. Mason JA, Parikh S, Tran H, Rowell J, McRae S. Australian multicentre study of current real-world prophylaxis practice in severe and moderate haemophilia A and B. *Haemophilia*. 2018;24:253–260.
60. Mahlangu J, Cerquiera M, Srivastava A. Emerging therapies for haemophilia – Global perspective. *Haemophilia*. 2018;24(Suppl. 6):15-21.
61. Peyvandi F, Garagiola I, Boscarino M, et al Real-life experience in switching to new extended half-life products at European haemophilia centres. *Haemophilia*. 2019;00:1–7.
62. Miesbach W, O’Mahony B, Key NS, Makris M. How to discuss gene therapy for haemophilia? A patient and physician perspective. *Haemophilia*. 2019;25:545–557.
63. Ascending Dose Study of Genome Editing by Zinc Finger Nuclease Therapeutic SB-FIX in Subjects With Severe Hemophilia B. *ClinicalTrials.gov*. *ClinicalTrials.gov Identifier*: NCT02695160
64. George, LA, Sullivan, SK, Giermasz, A et al. Hemophilia B gene therapy with a high-specific-activity factor IX variant. *N Engl J Med*. 2017;377(23):2215-2227.
65. Majowicz A, Nijmeijer B, Lampen MH, et al. Therapeutic hFIX activity achieved after single AAV5-hFIX treatment in hemophilia B Patients and NHPs with pre-existing Anti-AAV5 NABs. *Mol Ther Methods Clin Dev*. 2019 May 28;14:27-36.
66. Rangarajan, S, Walsh, L, Lester, W. AAV5–factor VIII gene transfer in severe hemophilia A. *N Engl J Med* 2017;377:2519-2530. doi: 10.1056/NEJMoa1708483
67. Stephens CJ, Lauronc EJ, Kashentsevaa E, Lu ZH, Yokoyama WM, Curiel DT. Long-term correction of hemophilia B using adenoviral delivery of CRISPR/Cas9. *J of Controlled Release*. 2019 Mar 28;298:128-141.
68. Favaloro EJ, Pasalic L, Curnow J. Diagnosis and management of von Willebrand disease in Australia. *Annals of Blood* 2018;3:31.
69. Leebeek FWG, Susen S. Von Willebrand disease: clinical conundrums. *Haemophilia* 2018;24(Suppl. 6):37-43.
70. Menegatti M, Peyvandi F. Treatment of rare factor deficiencies other than hemophilia. *Blood* 2019;133(5):415-424.
71. Nurden AT, Freson K, Seligsohn U. Inherited platelet disorders. *Haemophilia* 2012; 18 (Suppl. 4): 154–160.
72. Leebeek FWG, Susen S. Von Willebrand disease: Clinical conundrums. *Haemophilia*. 2018;24(Suppl. 6):37-43.
73. Dunn AL. Pathophysiology, diagnosis and prevention of arthropathy in patients with haemophilia *Haemophilia* 2011;17:571–578.
74. O’Hara J, Walsh S, Camp C. The impact of severe haemophilia and the presence of target joints on health-related quality-of-life. *Health and Quality of Life Outcomes* 2018;16:84
75. Siboni SM, Mannucci PM, Gringeri A, et al for the Italian Association of Haemophilia Centres (AICE). Health status and quality of life of elderly persons with severe hemophilia born before the advent of modern replacement therapy. *Journal of Thrombosis and Haemostasis* 2009;7:780–6.
76. Von Mackensen S, Gringeri A, Siboni SM, Mannucci PM, for the Italian Association of Haemophilia Centres. Health-related quality of life and psychological well-being in elderly patients with haemophilia. *Haemophilia* 2012; 18(3): 345-52.
77. Digby-Bowl CJ, Brown MB, Stephenson D. Postural stability is affected in older males with haemophilia—a matched control study. *Journal of Functional Morphology and Kinesiology*. 2018; 3(1):10.
78. Manucci PM, Schutgens REG, Santagostino E, Mauser-Bunschote EP. How I treat age-related morbidities in elderly persons with hemophilia. *Blood* 2009;114(26):5256-5263.
79. Wang K, Street A, Dowrick A, Liew S. Clinical outcomes and patient satisfaction following total joint replacement in haemophilia – 23-year experience in knees, hips and elbows. *Haemophilia* 2012;18: 86–93.
80. Klamroth R, Pollmann H, Hermans C, et al. The relative burden of haemophilia A and the impact of target joint development on health-related quality of life: results from the ADVATE Post-Authorization Safety Surveillance (PASS) study. *Haemophilia*. 2011 May;17(3):412-21.

81. van Vulpen LFD, Holstein K, Martinoli C. Joint disease in haemophilia: Pathophysiology, pain and imaging. *Haemophilia*. 2018;24(Suppl. 6):44–49.
82. Kurz E, Herbsleb M, Gabriel HHW, Hilberg T. Posturographic and ankle muscle activation characteristics in patients with haemophilia. *Haemophilia* 2019;25:136–143.
83. Fearn M, Hill K, Williams S, et al. Balance dysfunction in adults with haemophilia. *Haemophilia* 2010;16:606–614.
84. Hill K, Fearn M, Williams S, et al. Effectiveness of a balance training home exercise programme for adults with haemophilia: a pilot study. *Haemophilia* 2010;16:162–169.
85. Strike K, Mulder K, Michael R. Exercise for haemophilia. *Cochrane Database of Systematic Reviews* 2016, Issue 12. Art. No.: CD011180.
86. Siqueira TC, Dominski FH, Andrade A. Effects of exercise in people with haemophilia: An umbrella review of systematic reviews and meta-analyses. *Haemophilia* 2019;25:928–937.
87. Stephensen D, Rodriguez-Merchan EC. Orthopaedic co-morbidities in the elderly haemophilia population: a review. *Haemophilia* 2013;19:166–173.
88. Atiq F, Mauser-Bunschoten EP, Eikenboom J, et al.; for the WiN study group. Sports participation and physical activity in patients with von Willebrand disease. *Haemophilia*. 2019;25:101–108.
89. Skou ST, Roos EM. Good Life with osteoarthritis in Denmark (GLA:D™): evidence-based education and supervised neuromuscular exercise delivered by certified physiotherapists nationwide. *BMC Musculoskeletal* 2017;18:72.
90. Cramey C. Improve arthritic knee pain with exercise. *National Haemophilia* 2019 Sep;207:20-21.
91. Forsyth AL, Witkop M, Lambing A, et al. Associations of quality of life, pain, and self-reported arthritis with age, employment, bleed rate, and utilization of hemophilia treatment center and health care provider services: results in adults with hemophilia in the HERO study. *Patient Preference and Adherence* 2015;9:1549–1560.
92. Ceponis A, Wong-Sefidan I, Glass CS, von Drygalski A. Rapid musculoskeletal ultrasound for painful episodes in adult haemophilia patients. *Haemophilia* 2013; 19:790–798.
93. Lintzeris N, Driels J, Elias N, et al. Medicinal cannabis in Australia, 2016: the Cannabis as Medicine Survey (CAMS-16). *Medical Journal of Australia* 2018;209(5):211-216.
94. Butler DS, Moseley GL. Explain pain. 2nd ed. Noigroup: Adelaide, 2013.
95. Miesbach W, Reitter-Pfoertner S-E, Klamroth R, et al. Co-morbidities and bleeding in elderly patients with haemophilia—A survey of the German, Austrian and Swiss Society of Thrombosis and Haemostasis Research (GTH). *Haemophilia* 2017;23:721–727.
96. Marchesini E, Oliovecchio E, Coppola A, et al. Comorbidities in persons with haemophilia aged 60 years or more compared with age-matched people from the general population. *Haemophilia* 2018 Jan;24(1):e6-e10.
97. Poynard, T et al. Rates and risk factors of liver fibrosis progression in patients with chronic hepatitis C. *J of Hepatology* 2001; 34:730-9.
98. Australian Health Ministers' Advisory Council. Community Care and Population Health Principal Committee. Oral Health Monitoring Group. Healthy Mouths, Healthy Lives: Australia's National Oral Health Plan 2015–2024. COAG Health Council: Adelaide, 2015.
99. Haemophilia Foundation Australia. Getting it right: hepatitis C needs assessment evaluation and implementation report. HFA: Melbourne, 2009.
100. National Association of People with HIV Australia. HIV and ageing in Australia: the new frontier. NAPWA: Sydney, 2019.
101. McCarthy A. Looking forward to change with HIV. *National Haemophilia* 2017 Dec; 200:16-17.
102. Haemophilia Foundation Australia. Len's treatment story 2017. <<https://www.haemophilia.org.au/about-bleeding-disorders/personal-stories/hepatitis-c/len-s-treatment-story-2017> Accessed 12 March 2020 >
103. Haemophilia Foundation Australia. Paul's treatment story 2017. <<https://www.haemophilia.org.au/about-bleeding-disorders/personal-stories/hepatitis-c/paul-s-treatment-story-2017> Accessed 12 March 2020>
104. Peyvandi F, Tavakkoli F, Frame D, et al. Burden of mild haemophilia A: Systematic literature review. *Haemophilia*. 2019;25:755–763
105. Miesbach W, Berntorp E. When von Willebrand disease comes into age - a matter of change? *European Journal of Haematology* 2011 Jun;86(6):496-501.
106. Chapin J. Von Willebrand disease in the elderly: clinical perspectives. *Clinical Interventions in Aging*. 2018;13:1531-1541.
107. Renault, NK, Howell, RE, Robinson, S, et al. Qualitative assessment of the emotional and behavioural responses of haemophilia A carriers to negative experiences in their medical care. *Haemophilia* 2011;17:237-245.

108. Blanchette VS, Key NS, Ljung LR, Manco-Johnson MJ, van den Berg HM, Srivastava A, for the Subcommittee on Factor VIII, Factor IX and Rare Coagulation Disorders. Definitions in hemophilia: communication from the SSC of the ISTH. *Journal of Thrombosis and Haemostasis* 2014; 12: 1–5.
109. Osooli M, Donfield SM, Carlsson KS, et al. Joint comorbidities among Swedish carriers of haemophilia: A register-based cohort study over 22 years. *Haemophilia*. 2019;25:845–850.
110. Brown L, Hansnata E, La HA. The economic cost of dementia in Australia: 2016-2056. Institute for Governance and Policy Analysis: Canberra, 2017.
111. McLouglin C, Taylor PE. Don't go it alone: life satisfaction among older Australians according to the National Seniors Social Survey. Melbourne: National Seniors Productive Ageing Centre, 2016.
112. Hopwood M, Treloar C, Redsull L. Experiences of hepatitis C treatment and its management: what some patients and health professionals say. Monograph 4/2006. National Centre in HIV Social Research, University of NSW: Sydney, 2006.
113. Evatt BL. The natural evolution of haemophilia care: developing and sustaining comprehensive care globally. *Haemophilia* 2006;12(Suppl 3):13-21.
114. Australian Haemophilia Nurses' Group (AHNG); Australia/New Zealand Social Workers' and Counsellors' Group (ANZHSWCG). Caring for people with inherited bleeding disorders: information for staff working in residential care facilities. HFA: Melbourne, 2018.
115. Australian Haemophilia Nurses' Group (AHNG); Australia/New Zealand Social Workers' and Counsellors' Group (ANZHSWCG). Caring for people with inherited bleeding disorders: a fact sheet for staff working in residential care facilities. HFA: Melbourne, 2018.
116. Hollingdrake O, Mutch A, Zeissink B, Lawler SP, David M, Fitzgerald L. Haemophilia and age-related comorbidities: do men with haemophilia consult a general practitioner for men's preventative health checks? *Haemophilia* 2016;22: e301-e348.
117. Boccalandro E, Mancuso ME, Riva S, et al. Ageing successfully with haemophilia: A multidisciplinary programme. *Haemophilia* 2018;24:57–62.
118. Alberta AJ, Ploski RR, Carlson SL. Addressing challenges to providing peer-based recovery support. *The Journal of Behavioral Health Services & Research* 2012;39(4):481-91.
119. Kessler D, Egan M, Kubina LA. Peer support for stroke survivors: a case study. *BMC Health Services Research* 2014;14:256.
120. Omura K, Ito M, Eguchi E, et al. The effect of peer support groups on self-care for haemophilic patients with HIV in Japan. *Haemophilia* 2013;19(6):876-81.
121. Minty J. Women and peer support. *National Haemophilia March* 2019;205: 19-21.
122. Fearn M, Bhar S, Dunt D, Ames D, You E, Doyle C. Befriending to relieve anxiety and depression associated with chronic obstructive pulmonary disease (COPD): a case report. *Clinical Gerontologist*. 2017 May-Jun;40(3):207-212.
123. Australian Government. Australian Institute of Health and Welfare. Home ownership and housing tenure. 11 September 2019 < <https://www.aihw.gov.au/reports/australias-welfare/home-ownership-and-housing-tenure> Accessed 16 April 2020. >
124. Thornburg CD, Duncan NA. Treatment adherence in hemophilia. *Patient Preference and Adherence* 2017;11 1677–1686.
125. Aitken J. Healthy diet and managing weight: unlocking the myths. Presentation at the 19th Australian Conference on haemophilia, VWD & rare bleeding disorders, Sydney, 10-12 October 2019.
126. Royal Australian College of General Practitioners. The regulatory framework for medicinal use of cannabis products. Position statement – 2019 update. < <https://www.racgp.org.au/FSDEDEV/media/documents/RACGP/Position%20statements/Regulatory-framework-for-medicinal-use-of-cannabis-products.pdf> Accessed 7 May 2020 >
127. Australian Government. Senate Community Affairs Reference Committee. Hepatitis C and the blood supply in Australia. SCARC Secretariat: Canberra, 2004.
128. Australian Government. Productivity Commission. Impacts of health recommendations. Shifting the Dial: 5 year Productivity Review, Supporting Paper No. 6. Productivity Commission: Canberra, 2017.
129. O'Callaghan S. Policy update. *National Haemophilia Sep* 2017;199:21.