**HD RESOURCE LIST - WEBSITES & SUGGESTED READING MATERIAL**

**1. HDANI Huntington's Disease Association Northern Ireland - www.hdani.org.uk**

**Factsheets**

1. [Predictive Testing and Huntington's Disease](http://issuu.com/hdani/docs/predictive_testing_for_huntington_aecf18b804e088)
2. [Talking to Children about Huntington's Disease](http://issuu.com/hdani/docs/talking_to_children_about_huntingto_cdd767dcf669ff)
3. [Information for Teenagers](http://issuu.com/hdani/docs/information_forteenagers_2a3ff07b43f18c)
4. [Behavioural Problems and Huntington's Disease](http://issuu.com/hdani/docs/behaviour)
5. [Eating and Swallowing Difficulties](http://issuu.com/hdani/docs/eating_and_swallowing)
6. [Sexual Problems and Huntington's Disease](http://issuu.com/hdani/docs/sexual_problems)
7. [Huntington's Disease and Driving](http://issuu.com/hdani/docs/driving)
8. [Seating, Equipment and Adaptations](http://issuu.com/hdani/docs/seating__equipment_and_adaptations)
9. [Checklist for Choosing a Care Home](http://issuu.com/hdani/docs/choosing_a_care_home)

**Publications**

1. [Living with Huntington's Disease: A guide to the Early Stages](http://issuu.com/hdani/docs/hdani_family_handbook)(amended for N. Ireland)
2. [Understanding Behaviour](http://issuu.com/hdani/docs/understanding_behaviour)

**Wheelchair Services**

1. [Wheelchair Eligibility](https://docs.google.com/open?id=0B9W8EZ4xEfOgRlRFcURYcTdSNHF2TlZDckRwVl96Zw)(criteria for the provision of wheelchairs through the N. Ireland Wheelchair Service)
2. [Wheelchair Leads](https://docs.google.com/open?id=0B9W8EZ4xEfOgdnNKbktsRmhSdzJFeFdwUGcyNU1NQQ) (Who to contact in your area to resolve wheelchair issues)
3. [Wheelchair Services Action Plan](http://issuu.com/hdani/docs/wheelchair_regional_implementation_) (July 2010)

**Insurance Issues**

1. [Genetics Insurance Concordat.](http://issuu.com/hdani/docs/genetics_insurance_concordat)
2. [The ABI code of practice for genetic tests](http://issuu.com/hdani/docs/abi_code_of_practice_for_genetic_te)
3. [Guidance on genetic testing and sharing genetic information](http://issuu.com/hdani/docs/consent_and_confidentiality_in_gene)(Consent and confidentiality in genetic practice)

#### Fact Sheets for Healthcare Professionals:

* [Managing Behaviour in Huntington Disease](http://www.huntingtonsociety.ca/english/uploads/Behaviour_Health_Prof_FS.pdf)
* [Improving Communication in Huntington Disease](http://www.huntingtonsociety.ca/english/uploads/Communication_Health_Prof_FS.pdf)
* [Diet in Huntington Disease](http://www.huntingtonsociety.ca/english/uploads/Diet_Health_Prof_FS.pdf)[Palliative Care for Individuals in Late-Stage Huntington Disease](http://www.huntingtonsociety.ca/english/uploads/Palliative_care_Health_Prof.pdf)
* [End-of-Life Issues in Huntington Disease](http://www.huntingtonsociety.ca/english/uploads/End_of_Life_Health_Prof.pdf)
* [Exercise for People Living with Huntington Disease](http://www.huntingtonsociety.ca/english/uploads/Exercise_for_HD_FS.pdf)[Assessing Physiotherapy Needs of People Living with Huntington Disease](http://www.huntingtonsociety.ca/english/uploads/PT_assessment_health_prof_FS.pdf)[Physiotherapy Outcome Measures in Huntington Disease](http://www.huntingtonsociety.ca/english/uploads/PT_outcome_measures_health_prof_FS.pdf)
* [Minimizing Risk in Huntington Disease](http://www.huntingtonsociety.ca/english/uploads/Risk_Health_Prof_FS.pdf)

## **Video Guide for Health Professionals on Communication & Cognitive Issues** **“Hurry Up and Wait”**

This highly recommended video features Jimmy Pollard from Lowell, Massachusetts, USA. Jimmy is a renowned  HD specialist who has worked with Huntington’s patients for over 20 years. His understanding of communication and cognitive issues is legendary and his presentation is not only extremely informative, but delivered in a very engaging and entertaining way. Essential viewing for health care staff working with HD patients. Available on request (£10 inc. postage). \* Accompanying book details available below in additional HD Suggested Reading List.

Also available on HDANI Website are a number of HD PowerPoint Training Presentations and videos for your information.

**2. HDA England & Wales www.hda.org.uk**

Factsheets Available:

## HD

* [A Carer’s Guide](https://docs.google.com/a/hda.org.uk/uc?id=0B7QMCpPHjjhuVjNZVW9RVVo3RmM&export=download)
* [A Young Adult’s Guide](https://docs.google.com/a/hda.org.uk/uc?id=0B7QMCpPHjjhuNmpsZkhMaW0zWWM&export=download)
* [Advanced Decision to refuse Treatment (ADRT)](https://docs.google.com/a/hda.org.uk/uc?id=0B7QMCpPHjjhud2JPMTNKN1UzTmc&export=download)
* [Advice on Life Assurance, Pensions & Mortgages etc](https://docs.google.com/a/hda.org.uk/uc?id=0B7QMCpPHjjhuRHdlMHZvdnh4eGM&export=download)
* [Advice on Seating Equipment & Adaptations](https://docs.google.com/a/hda.org.uk/uc?id=0B7QMCpPHjjhudEFPMks1c0VkRUU&export=download)
* [Behavioural Problems](https://docs.google.com/a/hda.org.uk/uc?id=0B7QMCpPHjjhuZF9wZzZkQl8yUkE&export=download)
* [Choosing a Care Home](https://docs.google.com/a/hda.org.uk/uc?id=0B7QMCpPHjjhuQ1JTcHR5LWlfb00&export=download)
* [Communication Skills](https://docs.google.com/a/hda.org.uk/uc?id=0B7QMCpPHjjhubzN1aS1qUjBJeGM&export=download)
* [Eating & Swallowing](https://docs.google.com/a/hda.org.uk/uc?id=0B7QMCpPHjjhuZ0ZVV2hJMWZ3Mm8&export=download)
* [General Information](https://docs.google.com/a/hda.org.uk/uc?id=0B7QMCpPHjjhuSnZDenhjei02VG8&export=download)
* [HD & the Law](https://docs.google.com/a/hda.org.uk/uc?id=0B7QMCpPHjjhuMFJwY3VhZ3hpdlU&export=download)
* [Huntington's Disease & Diet](https://docs.google.com/a/hda.org.uk/uc?id=0B7QMCpPHjjhuUGlKTHllWU9LYzg&export=download)
* [Huntington's Disease & Driving](https://docs.google.com/a/hda.org.uk/uc?id=0B7QMCpPHjjhuSXJEV0x0elV6MHc&export=download)
* [Information for Teenagers](https://docs.google.com/a/hda.org.uk/uc?id=0B7QMCpPHjjhuMUtUemI5N2daVjQ&export=download)
* [Predictive Testing for Huntington](https://docs.google.com/a/hda.org.uk/uc?id=0B7QMCpPHjjhuMU84WF9xSHBuVTA&export=download)
* [Sexual Problems](https://docs.google.com/a/hda.org.uk/uc?id=0B7QMCpPHjjhuTVdxS3lYZEVLQ2c&export=download)
* [Talking to Children about HD](https://docs.google.com/a/hda.org.uk/uc?id=0B7QMCpPHjjhuTHgzX1NJUDJfeGM&export=download)
* [The Importance of Dental Care](https://docs.google.com/a/hda.org.uk/uc?id=0B7QMCpPHjjhuejA1RkN2Y0VQRk0&export=download)

## JHD

* [Challenging Behaviour in Juvenile HD](https://docs.google.com/a/hda.org.uk/uc?id=0B7QMCpPHjjhud2w0VFhoT0tTa1E&export=download)
* [Juvenile HD at School](https://docs.google.com/a/hda.org.uk/uc?id=0B7QMCpPHjjhuZFlXWFZObjF5VDQ&export=download)
* [Juvenile HD for Childrens Hospices & Palliative Care Services](https://docs.google.com/a/hda.org.uk/uc?id=0B7QMCpPHjjhuN0xLU3pQWElpWnM&export=download)

## 

## Professionals

* [Care in advanced HD Booklet](https://docs.google.com/a/hda.org.uk/uc?id=0B7QMCpPHjjhuSTBZaFFGbU1ELWM&export=download)
* [Guide to HD for GPs and Primary Care teams](https://docs.google.com/a/hda.org.uk/uc?id=0B0H_jrqJX7xeV0xsbjRtWXVpS0E&export=download)
* [HDA Referral Form for Professionals](https://docs.google.com/a/hda.org.uk/uc?id=0B0H_jrqJX7xeTmFnWm4wODlaZEU&export=download)
* [Huntington’s Disease - Doctor’s Guide](https://docs.google.com/feeds/download/documents/export/Export?id=1_pwqdIa_wobxRY52Wl87xG9H2P9V3YfG4zpEcn1ptag&exportFormat=pdf)
* [Huntington’s Disease - SALT & Dietician Guide](https://docs.google.com/feeds/download/documents/export/Export?id=1ZrMt5uMVgIYklkDXmqezauVOoZ1MXSluVqhVjnJ9EEk&exportFormat=pdf)
* [Huntington’s Disease Care Pathway](https://docs.google.com/feeds/download/documents/export/Export?id=1OUUt3zw9b_q4aK3DXJ78yR_Iuu3jW3PPbCHo7pUF6rs&exportFormat=pdf)
* [Huntington’s Disease Standards of Care](https://docs.google.com/a/hda.org.uk/uc?id=0B0H_jrqJX7xeMjVycnM5WXMyQVE&export=download)
* [Malnutrition and eating difficulties](https://docs.google.com/feeds/download/documents/export/Export?id=1-lNRf54JRmfbtzrd0GlpdaqpV49GMvvNiU8CIXRFYm0&exportFormat=pdf)
* [Mental Illness and Capacity in HD](https://docs.google.com/a/hda.org.uk/uc?id=0B0H_jrqJX7xeZTZyYlRNSnhTc2s&export=download)
* [Nutritional Management of People with HD](https://docs.google.com/a/hda.org.uk/uc?id=0B0H_jrqJX7xeWlZpMlVzaTlFZG8&export=download)
* [Occupational Therapy for people with HD](https://docs.google.com/a/hda.org.uk/uc?id=0B0H_jrqJX7xeV0NrQ2RUTWNWeEk&export=download)
* [Occupational Therapy in HD](https://docs.google.com/feeds/download/documents/export/Export?id=1S4VwaKDbrbwh9mPX_WUc1PpK5OJLt2rvGvapp9mlomY&exportFormat=pdf)
* [Physical Therapy Intervention for People with Huntington Disease](https://docs.google.com/a/hda.org.uk/uc?id=0B0H_jrqJX7xeR19PS0tzNXZsYlU&export=download)
* [Physical Therapy and HD](https://docs.google.com/feeds/download/documents/export/Export?id=1Cw3yPEZzWXgivXatosf44lbjt7JqzbnJX7N1_flXTS8&exportFormat=pdf)
* [Physical and Occupational Therapy for Huntington’s Disease](https://docs.google.com/feeds/download/documents/export/Export?id=1gAvSD6WxWOP8LwTexPewBiLOwx_5vSZ0u-5YjX4-wpY&exportFormat=pdf)
* [Standards of Care for Care Homes](https://docs.google.com/a/hda.org.uk/uc?id=0B0H_jrqJX7xeczFoYm42X09aLTg&export=download)
* [The role of the physiotherapist in Huntington’s disease](https://docs.google.com/feeds/download/documents/export/Export?id=1NEihsE6XIRxpYqdqpxCpyynnR5bP2pYpzHz7DdVy2vc&exportFormat=pdf)

**3. Huntington's Disease Association of Ireland www.huntingtons.ie**

* HDAI Caregivers Guide
* HDAI Physicians Guide
* HDAI Understanding Behaviour

**4. Huntington's Disease Society of America www.hdsa.org**

* A Physician's Guide to the Management of Huntington's Disease 3rd Edition
* Caregiver Guide
* HDSA Family Guide Series: Speech, Language & Swallowing Difficulties

Physical Occupational Therapy

**5. Huntington Society of Canada www.huntingtonsociety.ca**

Factsheets for healthcare professionals.

* Have you M.E.T. Huntington Disease (HD)
* Managing Behaviour in Huntington Disease
* Eating & Swallowing
* Juvenile Huntington Disease
* 2015HD Clinical Trials

**Additional Links and Resources:**

* [International Huntington Association](http://www.huntington-assoc.com/)
* [HD Buzz](http://en.hdbuzz.net/056) Research News
* [Scottish Huntington's Association](http://www.hdscotland.org/)
* [European Huntington's Disease Network](http://www.euro-hd.net/html/network?eurohdsid=7c1189064695563d783c7269164dbae4)
* [Hereditary Disease Foundation](http://www.hdfoundation.org/)
* [Huntington Study Group](http://www.huntington-study-group.org/)
* [Huntington's Lighthouse](http://www.hdlighthouse.org/)
* N I Rare Disease Partnership

\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*

**Additional HD Suggested Reading List**:

HENNIG, Bonnie, L, MSW, LCSW: *'Talking to Kids About Huntington's Disease'* - A book for people who know children with HD in their family. ($14-99 available @ www.talkingtokidsabouthd.com)

POLLARD, Jimmy: *'Hurry Up And Wait!* - A Cognitive Care Companion (approx £8 available @ <http://www.lulu.com/gb/en/shop/james-pollard/hurry-up-and-wait/paperback/product-3610588.html> \* Accompanying DVD available from HDANI £10 www.hdani.org.uk

SMITH Steve: *'Huntington's Disease A Nursing Guide'*, Applying the Roper Logan and Tierney Model of Nursing 2005 (available @ www.fernhouse.com) ISBN 1 902702 10 7

SULAIMAN Sandy: *'Learning to Live with Huntington's Disease - One Family's Story'*. Jessica Kingsley Publishers London and Philadelphia.

VAN BROEKHOVEN-GRUTTERS, Ellen; GAASBEEK, Dirk; VENINGA-VERBAAS, Maartje: *'Nutrition and Huntington's Disease, A Practical Guide'*, A Multidisciplinary Approach Manual For Medical Practitioners And Paramedics. Publisher: Atlant Zorggroep, Apeldoorn - Beekbergen, The Netherlands ISBN 90-805882-1-0

**Health Trust Websites:**

<http://www.northerntrust.hscni.net/pdf/Carers_A_to_Z_guide.pdf>

<http://www.belfasttrust.hscni.net/Services.htm>

<http://www.setrust.hscni.net/services/2561.htm>

<http://www.westerntrust.hscni.net/services/ServicesA-Z.htm>

<http://www.southerntrust.hscni.net/services.htm>