A-Z Resources for Patients

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| Resource/ Leaflet Name: | Produced by: | Ordered from: |
| Blood and/ or Transfusion |  |  |
| Blood Donation - Who would you bleed for? Save a life give blood. | NHS Blood and Transplant | Order is from the NHSBT website.To order or print:<https://hospital.blood.co.uk/patient-services/patient-blood-management/patient-information-leaflets/> |
| FerriScan – Preparing yourself for a Ferriscan | Resonance Health: Be better Informed | Leaflets are sent by the UK Rep. To find who the current rep is, make a query to Resonance Health. <https://www.resonancehealth.com/contact/> |
| Information for patients with SCD who need a blood transfusion. | NHS Blood and Transplant – new leaflet  | <https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/29011/inf1308.pdf> |
| Preparing your child for a Ferriscan | Resonance Health: Be better Informed | Contact Resonance Health for the leaflet<https://www.resonancehealth.com/contact/> |
| Receiving Blood Transfusion: Information for patients and their families, carers and guardians | NHS Blood and Transplant | To order or print:<https://hospital.blood.co.uk/patient-services/patient-blood-management/patient-information-leaflets/>For different formats email:NHSBTcustomerservice@nhsbt.nhs.uk |
| Red Cell Exchange Top Tips | Wessex and Thames Valley HCC | Print from the NSSG website<https://nssg.oxford-haematology.org.uk/red-cell/documents/patient-information/S81-red-cell-exchanges-top-tips.pdf> |
| Therapeutic Apheresis Service: Patient information leaflet – Red cell exchange procedure | NHS Blood and Transplant | To order or print:<https://hospital.blood.co.uk/patient-services/patient-blood-management/patient-information-leaflets/> |
| Transfusion dependent Thalassaemia – 1 hour per unit | Wessex and Thames Valley HCC | Print from the NSSG website<https://nssg.oxford-haematology.org.uk/red-cell/documents/patient-information/S73-2-patient-information-one-hour-per-unit-blood-transfusion-in-tdt.pdf> |
| Carers information |  |  |
| Supporting someone at home? We can help | Carers Oxfordshire | Contact Carers Oxfordshire for a leaflet [www.carersoxfordshire.org.uk](http://www.carersoxfordshire.org.uk) |
| Dental and Teeth |  |  |
| How to take care of your teeth | Community Dental Services | [www.communitydentalservices.co.uk](http://www.communitydentalservices.co.uk)Booklets & videos: <https://www.communitydentalservices.co.uk/patient-information/easy-read/>To order patient information: <https://www.communitydentalservices.co.uk/contact/> |
| DLA and PIP |  |  |
| DLA and PIP applications  | Wessex and Thames Valley HCC | Print from the NSSG website<https://nssg.oxford-haematology.org.uk/red-cell/documents/patient-information/S65-dla-and-pip.pdf> |
| Employment & Cost of Living |  |  |
| Careers Information  | Wessex and Thames Valley HCC | Print from the NSSG website<https://nssg.oxford-haematology.org.uk/red-cell/documents/patient-information/S64-careers-information.pdf> |
| Employment: Sickle Cell and Work Employment | Simon Dyson and Maria Berghs (De Montford University); Sickle cell society and OSCAR Sandwell. | pdf guide can be printed -> <https://sicklecellwork.dmu.ac.uk/> or from the NSSG website<https://nssg.oxford-haematology.org.uk/red-cell/documents/patient-information/guide-to-sickle-cell-and-employment.pdf> |
| Ideas for managing energy efficiency and rising energy costs | Wessex and Thames Valley HCC | Print from the NSSG website<https://nssg.oxford-haematology.org.uk/red-cell/documents/patient-information/ideas-for-managing-energy-efficiency-and-rising-energy-costs-sept-2022.pdf> |
| Enuresis  |  |  |
| Enuresis in children with sickle cell disease | Wessex and Thames Valley HCCERIC website | <https://nssg.oxford-haematology.org.uk/red-cell-paeds/documents/patient-information/PH30-enuresis-in-sickle-cell.pdf><https://eric.org.uk/> |
| Exercises |  |  |
| Active 10 programme:10 Steps to an Active You | Public Health England | Account with PHE is needed to order any leaflets or booklets.  |
| Exercises for Computer Users | Centre for Occupational Health and Wellbeing, OUH NHS Foundation trust | Print from the Internal OUH Intranet. |
| G6PD Deficiency |  |  |
| G6PD Deficiency: Information for patients, parents or carers | Wessex and Thames Valley HCC | To print:<https://nssg.oxford-haematology.org.uk/red-cell/documents/patient-information/S80-G6PD-deficiency-patient-information.pdf> |
| Haemoglobin H Disease |  |  |
| Haemoglobin H Disease: Information for patients, parents or carers | Wessex and Thames Valley HCC | To print: <https://nssg.oxford-haematology.org.uk/red-cell/documents/patient-information/S76-haemoglobin-h-disease-pi.pdf> |
| Hereditary Spherocytosis |  |  |
| Hereditary Spherocytosis: Information for patients and parents | Congenital Anaemia Network (CAN) | Leaflet created by CAN<https://togetherwecan.uk/wp-content/uploads/2018/04/HS_CAN_leaflet.pdf>CAN contact detail info@togetherwecan.uk |
| Hydroxycarbamide |  |  |
| Hydroxycarbamide for people with SCD | Wessex and Thames Valley HCC | Print from the NSSG website<https://nssg.oxford-haematology.org.uk/red-cell/documents/patient-information/S48-hydroxycarbamide-patient-information.pdf> |
| Hydroxycarbamide liquid (Xromi) | http://supersickle.com/code: NovaLabs123SSD | Downloadable resources from Nova labsOr contact Nova labs rep for all hard copiesPatient testimonials:<https://www.nova-knowledge.co.uk/hcp/xromi/case-studies/titus-story><https://www.nova-knowledge.co.uk/hcp/xromi/case-studies/lauras-story> |
| Incentive Spirometry |  |  |
| Incentive Spirometry: Patient Information | Wessex and Thames Valley HCC | Print from the NSSG website:<https://nssg.oxford-haematology.org.uk/red-cell/documents/acute-management-sickle-cell-disease/S52-how-to-use-an-incentive-spirometer.pdf> |
| Needle Phobia |  |  |
| Injection phobia: a brief guide | Anxiety UK | Available on the NSSG website:<https://nssg.oxford-haematology.org.uk/red-cell/documents/patient-information/needle-phobia-booklet.pdf> |
| Nutrition |  |  |
| 10 Minutes to change your life – Time to eat well | British Heart Foundation | To print:<https://www.bhf.org.uk/informationsupport/publications/healthy-eating-and-drinking/10-minutes-to-change-your-life---time-to-eat-well-challenge-chart> |
| Be a healthy Weight leaflet | Cancer Prevention- Together we can  | To order email: wcrf@wcrf.orgCall: 020 7343 4200Website: [www.wcrf-uk.org](http://www.wcrf-uk.org) |
| Eat Better Booklet | British Heart Foundation | To print:<https://www.bhf.org.uk/informationsupport/publications/healthy-eating-and-drinking/eat-better> |
| Food Fact Sheets (given as a pack)* Eat Well, Spend Less
* Portion sizes
* Healthy Eating
* Plant-Based Diet
 | BDA The Association of UK Dietitians | Print from the BDA website.<https://www.bda.uk.com/> |
| Food Fact Sheets: Iron | BDA The Association of UK Dietitians | Print from the BDA website.<https://www.bda.uk.com/resourceDetail/printPdf/?resource=iron-rich-foods-iron-deficiency> |
| Food Fact Sheets: (Given as a pack)* Osteoporosis
* Vitamin D
* Calcium
* Folic Acid
 | BDA The Association of UK Dietitians | Print from the BDA website.<https://www.bda.uk.com/> |
| Nutrition Support: Improving your protein and energy intake | OUH NHS Foundation Trust | Print from the Oxford University Hospitals NNHS FT website:<https://www.ouh.nhs.uk/patient-guide/leaflets/files/69128Pnutrition.pdf>Link is also available on the NSSG website under patient information. |
| Food Fact Sheets: Weight Loss | BDA The Association of UK Dietitians | Print from the BDA website<https://www.bda.uk.com/resource/weight-loss.html><https://www.bda.uk.com/uploads/assets/c5761f35-ec82-4449-9fed3bcfe1fd08a5/Weight-loss-food-fact-sheet.pdf> |
| Portacath |  |  |
| Patient advice: Portacath | Wessex and Thames Valley HCC | Print from the NSSG website<https://nssg.oxford-haematology.org.uk/red-cell/documents/patient-information/S60-1-vortex-portacath-patient-advice.pdf> |
| Priapism |  |  |
| Priapism: Information for patients, parents and carers | Wessex and Thames Valley HCC | Print from the NSSG website <https://nssg.oxford-haematology.org.uk/red-cell/documents/patient-information/S49-priapism-patient-information.pdf> |
| Priapism | Sickle Cell Society | <https://www.sicklecellsociety.org/priapism/> |
| Retinopathy |  |  |
| SCD and Retinopathy: Information for patients | Wessex and Thames Valley HCC | Print from the NSSG Website<https://nssg.oxford-haematology.org.uk/red-cell/documents/patient-information/S20-1-pi-sickle-retinopathy.pdf> |
| Sexual Health |  |  |
| Oxfordshire Sexual Health Service: Business Cards | OUH NHS FT and Oxfordshire County Council | To order contact: <https://www.sexualhealthoxfordshire.nhs.uk/contact/> |
| Sickle Cell  |  |  |
| Test for dads | Public health England | Print from PHE website<https://www.gov.uk/government/publications/tests-for-dads-sickle-cell-and-thalassaemia-screening> |
| Baby at risk of having sickle cell disease: description in brief | Public Health England | Print from the UK Gov Website<https://www.gov.uk/government/publications/baby-at-risk-of-having-sickle-cell-disease-description-in-brief> |
| Pregnancy: Screening for sickle cell and thalassaemia | NHS | <https://www.nhs.uk/pregnancy/your-pregnancy-care/screening-for-sickle-cell-and-thalassaemia/> |
| Parent Guide to managing sickle cell | Sickle Cell Society | Download the booklet from:<https://www.sicklecellsociety.org/resource/parentsguide/>To order booklets: Contact the sickle cell society |
| Did you know? 5-10 years | Sickle Cell Society | Booklet available:<https://www.sicklecellsociety.org/resource/know-age-5-10-information-booklet-children/> |
| Did you know 11-16 years | Sickle Cell Society | Booklet available:<https://www.sicklecellsociety.org/resource/did-you-know-age-11-16-an-information-booklet-for-young-people/> |
| ‘My Friend Jen’ | Story of girl who has sickle cell disease | Contact CAN for more copies<https://togetherwecan.uk/> |
| Sleep |  |  |
| Trouble Sleeping?  | Sleepio | Free for patients in the Thames Valley Network[www.sleepio.com/nhs](http://www.sleepio.com/nhs)email: hello@sleepio.com |
| Sleep – HCC Patient Information Leaflet | Wessex and Thames Valley HCC | Print from the NSSG website<https://nssg.oxford-haematology.org.uk/red-cell/documents/patient-information/S77-sleep-information.pdf> |
| Spleen Information |  |  |
| Information for patients with an absent or dysfunctional spleen | Health and Social Care order line | Please register at [www.healthpublications.gov.uk](http://www.healthpublications.gov.uk) |
| Splenectomy: Information for patientsInformation for patients without a working spleen | UK Health Security Agency | Leaflet available for print from UK GOV website:<https://www.gov.uk/government/publications/splenectomy-leaflet-and-card> |
| Stem Cell Transplant |  |  |
| Information about Stem Cell Transplant | Anthony Nolan | <https://www.anthonynolan.org/patients-and-families/blood-cancers-and-blood-disorders/what-a-blood-disorder/sickle-cell-disease> |
| Thalassaemia |  |  |
| Baby at risk of having thalassaemia: description in brief | Public Health England | <https://www.gov.uk/government/publications/baby-at-risk-of-having-thalassaemia-description-in-brief> |
| My baby has Thalassaemia | UKTS | Booklet available:<https://ukts.org/new-diagnosis/> |
| Travel |  |  |
| Travel information for people with Sickle Cell disease, thal and rare anaemia | Wessex and Thames Valley HCC | Print from the NSSG website<https://nssg.oxford-haematology.org.uk/red-cell/documents/patient-information/S63-travel-advice-sickle-cell-and-thalassaemia.pdf> |
| Travelling and Thrombosis Risk – Information for patients | Oxford University Hospital NHS Foundation Trust | Available on the OUH website. Oxford can order it via the Print Room.<https://www.ouh.nhs.uk/patient-guide/leaflets/files/79307Ptravelling.pdf> |
| Transition/ Moving into the adult service |  |  |
| Moving to the adult haemoglobinopathy service | Wessex and Thames Valley HCC | Print from the NSSG website:<https://nssg.oxford-haematology.org.uk/red-cell/documents/patient-information/S88-pi-moving-to-the-adult-service-transition.pdf> |
| Ready steady go |  | <https://www.readysteadygo.net/rsg.html> |
| How to adult | Bay Youth Group | <https://nssg.oxford-haematology.org.uk/red-cell-paeds/documents/transition/rcpch-us-how-2-adult.pdf> |
| Ask 3 questions | NHS | <https://www.readysteadygo.net/shared-decision-making--ask-three-questions.html> |
| Youth’s rights in healthcare | British Youth Council | <https://www.byc.org.uk/uk/nhs-youth-forum/youth-rights-in-healthcare> |
| Vaccinations |  |  |
| Pneumococcal Vaccine | NHS  | <https://www.nhs.uk/conditions/vaccinations/pneumococcal-vaccination/>Print from the website. |
| Wellbeing |  |  |
| How to improve your mental wellbeing | Every Mind Matters, NHS | Print from: <https://www.mind.org.uk/information-support/tips-for-everyday-living/wellbeing/wellbeing/>  |
| Every Mind Matters - Foldable cardIt includes:- low mood, anxiety, sleep and stress | Public Health England | Sign up to Public Health England – for regular updatesLink to resources: <https://campaignresources.phe.gov.uk/resources/campaigns/111-better-health---every-mind-matters/resources> |
| Fatigue diary  | Wessex and Thames Valley HCC | Print from the NSSG Website<https://nssg.oxford-haematology.org.uk/red-cell/documents/patient-information/S53-fatigue-diary.pdf> |
| Help with Anxiety and Depression | Talking Space PLUS | For People in Oxfordshire onlyWebsite: [www.talkingspaceplus.org.uk](http://www.talkingspaceplus.org.uk)Email talkingspaceplus@nhs.net |
| How are you? - Foldable cardIt includes:- Eat well, move more, be smoke free, drink less, check yourself, stress less, sleep better | Public Health England | Sign up to Public Health England – for regular updates |
| Standing Exercise Programme – Advice for outpatients | Oxford University Hospital NHS Foundation Trust | Available in Oxford only, ordered and printedlocally, via the Print Room. |