



RESOURCE GUIDE FOR NEW JERSEY FAMILIES LIVING WITH HUNTINGTON'S DISEASE

Created by:

Corlynn Hullfish, LCSW
chullfish@hdsa.org

Kayla Cupano OTD-S
kcotd0@gmail.com

TABLE OF CONTENTS

COUNTY SOCIAL SERVICE AGENCIES..... 4-5

HELP WITH CAREGIVING 6

ADULT PROTECTIVE SERVICES BY NJ COUNTY 7

DESIGNATED PSYCHIATRIC SCREENING/CRISIS CENTERS 8-10

MENTAL HEALTH AND HOMELESSNESS PREVENTION SERVICES.....10-12

NURSING HOMES WITH DEDICATED HD UNITS 12

HDSA SUPPORT GROUPS 12

ONLINE SUPPORT GROUPS BY HDSA 12

HD COUNSELING SUPPORT..... 12

SOCIAL CLUBS12-13

HDSA NJ CENTER OF EXCELLENCE SPECIALIZING IN HD CARE..... 13

OTHER CENTERS SPECIALIZING IN HD CARE NEAR NJ 13

INDEPENDENT NJ PHYSICIANS TREATING HD13-14

ELDER CARE/DISABILITY ATTORNEYS.....14-15

DRIVING EVALUATIONS..... 15

SWALLOWING STUDIES 16

COOKBOOKS AND NUTRITION..... 16

LOW COST/FREE MEDICAL EQUIPMENT..... 16

DISABILITY QUESTIONS ANSWERED..... 16

HELP WITH LONG TERM MEDICAID APPLICATIONS/QUESTIONS(MLTSS) 16

HELP WITH MEDICARE PLANS..... 16

PGD AND GENETIC COUNSELING 17

HELP WITH MEDICATIONS..... 17

BRAIN DONATION..... .17

HD RELATED FINANCIAL ASSISTANCE..... .18-19

THERAPY FOR INDIVIDUALS WITH HD.....19
LONG TERM CARE 19
HOME SAFETY EVALUATIONS.....20
HD YOUTH.....20
INTERNET RESOURCES..... 20-21
CRISIS FLOW SHEET.....22

COUNTY SOCIAL SERVICES AGENCIES

Atlantic County

Department of Family and Community
Development

1333 Atlantic Ave, Atlantic City, NJ
08401 (609) 348-3001
Fax: (609) 343-2374
Hours: 8:00 AM - 5:00 PM

Bergen County

Bergen County Board of Social Services

218 Route 17 North - Building A
Rochelle Park, NJ 07662
(201) 368-4200, Fax: (201) 368-8710
Hours: 7:45 AM- 4:45 PM Tues. till 8:00 PM

Burlington County

Burlington County Board of Social Services

795 Woodlane Road, Mount Holly, NJ 08060
(609) 261-1000, Fax: (609) 261-0463
Hours: 8:00 AM - 5:00 PM

Camden County

Camden County Board of Social Services

600 Market Street, Camden, NJ 08102-1255
(856) 225-8800, Fax: (856) 225-7797
Hours: 8:30 AM -4:30 AM

Hudson County

Hudson County Dept of Family Services

257 Cornelison Ave., Jersey City, NJ 07302
(201) 420-3000, Fax: (201) 420-0343
Hours: 8:00 AM - 4:15 PM

Cape May County

Cape May County Board of Social Services

4005 Route 9 South, Rio Grande, NJ 08242
(609) 886-6200, Fax: (609) 889-9332
Hours: 8:30 AM - 4:30 PM

Cumberland County

Cumberland County Board of Social Services

275 North Delsea Dr., Vineland, NJ 08360
(856) 691-4600, Fax: (856) 692-7635
Hours: 8:30 AM - 4:30 PM

Essex County

Essex County Dept of Citizen Services

18 Rector Street - 9th Fl, Newark, NJ 07102
(973) 733-3000, Fax: (973) 643-3985
Hours: 7:30 AM -4:00 PM Weds by appt
*Closed to public every 3rd Thursday

Gloucester County

Gloucester County Social Services

400 Hollydell Drive, Sewell, NJ 08080
(856) 582-9200, Fax: (856) 582-6587
Hours: 8:30 AM - 4:30 PM
1st & 3rd Tues. 8:30 AM - 6:30 PM

Monmouth County

Division of Social Services

PO Box 3000
3000 Kozloski Road, Freehold, NJ 07728
(732) 431-6000, Fax: (732) 431-6017
Freehold Hours: 8:30 AM - 4:40 PM
Thurs.: 8:30 AM - 8:00 PM
Ocean Field Office: 8:30 AM - 4:30 PM
Tues. & Weds.: 8:30 AM - 8:00 PM

Hunterdon County

Division of Social Services

6 Gauntt Place, Flemington, NJ 08822
(908) 788-1300, Fax: (908) 806-4588
Hours: 8:30 AM - 4:30 AM

Mercer County

Mercer County Board of Social Services

200 Woolverton Street, Trenton, NJ 08611
(609) 989-4320, Fax: (609) 989-0405
Hours: 8:30 AM - 4:30 PM
Tues.: 8:30 AM - 8:30 PM

Middlesex County

Middlesex County Board of Social Services

181 How Lane New Brunswick, NJ 08903
(732) 745-3500, Fax: (732) 745-4558
Hours: 8:30 AM - 4:15 PM

Passaic County

Passaic County Board of Social Services

80 Hamilton St., Paterson, NJ 07505-2057
(973) 881-0100, Fax: (973) 881-3232
Hours: 7:30 AM - 4:30 PM
(Doors are closed to the public at 4:15 PM)

Salem County

Salem County Board of Social Services

147 S Virginia Ave, Penns Grove, NJ 08069
(856) 299-7200, Fax: (856) 299-3245
Hours: 8:00 AM - 4:00 PM

Somerset County

Somerset County Board of Social Services

PO Box 936
73 East High St. Somerville, NJ 08876
(908) 526-8800, Fax: (908) 231-9010
Hours: 8:15 AM – 6:00 PM

Morris County

Office of Temporary Assistance

340 W. Hanover Ave
Morristown, NJ 07960
(973) 326-7800, Fax: 973-326-7875
Hours: 8:30 AM -4:30 PM
Every Other Tues.: 8:30 -7:30 PM

Ocean County

Ocean County Board of Social Services

1027 Hooper Avenue, Toms River, NJ 08753
(732) 349-1500, Fax: (732) 244-8075
Hours: 8:30 AM - 4:30 PM
Tues.: 8:30 AM - 6:00 PM

Sussex County

Sussex County Division of Social Services

83 Spring Street, Suite 203
Newton, NJ 07860
(973) 383-3600, Fax: 973-579-9894
Hours: 8:30 AM - 4:30 PM

Union County

Union County Division of Social Services

342 Westminster Ave., Elizabeth, NJ 07208
(908) 965-2700, Fax: (908) 965-2752
Hours: 8:30 AM - 4:30 PM

Warren County

Division of Temporary Assistance
and Social Services

1 Shotwell Dr., Belvidere, NJ 07823
(908) 475-6301, Fax: (908) 475-1533
Hours: 8:30 AM - 4:30 PM

HELP WITH CAREGIVING

Aging & Disability Resource Connection/Area Agency on Aging (ADRC/AAA)

An Area Agency on Aging (AAA) is designated in each of New Jersey's 21 counties to serve as the primary entity responsible for developing comprehensive, coordinated systems of community-based services for older adults.

Toll Free Nationwide: 1-877- 222-3737

<http://www.adrcnj.org/> “A Guide to Community Based Long-term Care in NJ”

Managed Long-term Services and Supports (MLTSS)

Managed Long Term Services and Supports (MLTSS) refers to the delivery of long-term services and supports through New Jersey Medicaid's NJ Family Care managed care program. MLTSS is designed to expand home and community-based services, promote community inclusion and ensure quality and efficiency.

Managed Long Term Services and Supports (MLTSS) includes: Personal Care; Respite; Care Management; Home and Vehicle Modifications; Home Delivered Meals; Personal Emergency Response Systems; Mental Health and Addiction Services; Assisted Living; Community Residential Services; and Nursing Home Care.

Contact your local Board of Social Services or call: 1-877- 222-3737

Jersey Assistance for Community Caregiving (JACC)

JACC is a State-funded program (for people who are not Medicaid eligible) that provides a broad array of in-home services to enable an individual, at risk of placement in a nursing facility and who meets income and resource requirements, to remain in his or her community home. By providing a uniquely designed package of supports for the individual, JACC delays or prevents placement in a nursing facility.

Individuals interested in receiving services through JACC may contact the Aging & Disability Resource Connection (ADRC) site in their county.

Their local ADRC can be reached toll free by dialing: 1-877-222-3737.

ADRC workers will assist callers and refer individuals to the proper application point

Statewide Respite Program

This program provides respite care services for elderly and functionally impaired persons age 18 and older to relieve their unpaid caregivers of stress arising from the responsibility of providing daily care. A secondary goal of the program is to provide the support necessary to help families avoid making nursing home placement of their relatives. Services available under the Statewide Respite Care Program include: Companions, homemaker/home health aides (on an hourly or overnight basis), medical or social adult day care, temporary care in licensed medical facilities, camperships, private duty nursing service, and caregiver-directed option.

To reach the Statewide Respite Care Program in your county, call Aging & Disability Resource Connection (ADRC) toll-free at: 1-877-222-3737

ADULT PROTECTIVE SERVICES BY NJ COUNTY

<u>COUNTY</u>	<u>PHONE</u>	<u>AFTER HOURS PHONE</u>
ATLANTIC	609-645-7700 x4348	888-426-9243
BERGEN	201-368-4300	800-624-0275
BURLINGTON	609-261-1000 X4797	609-267-8500
CAMDEN	856-225-8178	800-786-5080
CAPE MAY	609-886-6200 X358	911
CUMBERLAND	856-825-6810 X219	856-455-5555
ESSEX	973-624-2528 X135	911
GLOUCESTER	856-582-9200	800-648-0132
HUDSON	201-295-5160	800-792-8610
HUNTERDON	908-788-1300	800-272-4630
MERCER	609-989-4346	911
MIDDLESEX	732-745-3635	911
MONMOUTH	732-531-9191	732-531-9111
MORRIS	973-326-7282	973-285-2900
OCEAN	732-349-1500/732-286-5929	732-240-6100
PASSAIC	973-881-2616/881-0100	973-345-2676
SALEM	856-935-7510	911
SOMERSET	908-526-8800	800-287-3607
SUSSEX	973-383-3600X140	800-280-8845
UNION	908-497-3900/497-3902	911
WARREN	908-475-6301	911

**DESIGNATED PSYCHIATRIC
SCREENING/CRISIS CENTERS**

08210 HOTLINE: (609) 465-5999

Atlantic County

Psychiatric Intervention Program (PIP)
@ Atlanticare Regional Medical Center
1925 Pacific Avenue Atlantic City, NJ
08401 HOTLINE: (609) 344-1118

Bergen County

Psychiatric Emergency Screening Care
Plus NJ Inc. @ Bergen Regional Medical
Center
230 East Ridgewood Avenue
Paramus, NJ 07652
HOTLINE: (201) 262-4357

Burlington County

Legacy Treatment Services
Lords Medical Center
218A Sunset Road
Willingboro, NJ 08046
HOTLINE: (609) 835-6180

Camden County

Oaks Integrated Care
@ Kennedy Memorial Hospital
2201 West Chapel
Ave. Cherry Hill, NJ
08002
HOTLINE:
(856) 428- 4357

Cape May County

Acenda Integrated Health
Cape Medical Regional Center
2 Stone Harbor Blvd.
Cape May Court House, NJ

Cumberland County

Cumberland County Guidance Center
@ Inspira Medical Centers
333 Irving Avenue
Bridgeton, NJ 08302
HOTLINE: (856) 455-5555

Essex County

Clara Maass Medical Center
1 Clara Maass Drive.
Bellville, NJ 07109
HOTLINE: (973) 844-4357

Newark Beth Israel Medical Center
201 Lyons Avenue
Newark, NJ 07112
HOTLINE: (973) 926-7444

University Behavioral Health Care
150 Bergen Street
Newark, NJ 07101
HOTLINE: (973) 623-2323

Gloucester County

Acenda Integrated Health
42 South Delsea Drive
Glassboro, NJ 08028
HOTLINE: (856) 845-9100

Hudson County

Jersey City Medical Center
355 Grand Street
Jersey City, NJ 07340
HOTLINE: (866) 367-6023

Palisades Medical
Center AES
7600 River Road
North Bergen, NJ 07047
HOTLINE: (201) 854-6300

Christ Hospital
AES
176 Palisade
Avenue.
Jersey City, NJ
07304
HOTLINE: (201) 795-8374

Hoboken University
Medical Center AES
308 Willow Avenue
Hoboken, NJ 07030
HOTLINE: (201) 418-2090

Hunterdon County

Hunterdon Medical Center
Emergency Svcs Behavioral
Health 2100 Wescott Drive
Flemington, NJ 08822
HOTLINE: (908) 788-6400

Mercer County

Capital Health Regional
Medical Center
750 Brunswick Avenue
Trenton, NJ 08638
HOTLINES: (609) 396-4357 or
(609) 989-7297

Middlesex County

University Behavioral
Health Care
671 Hoes Lane

Piscataway, NJ 08855
HOTLINE: (732) 235-5700

Raritan Bay Medical Center AES
530 New Brunswick Avenue Perth
Amboy, NJ 08861
HOTLINE: (732) 442-3794

Monmouth County

Monmouth Medical Center
300 Second Avenue
Long Branch, NJ 07740
HOTLINE: (732) 923-6999

Centra State Medical Center AES
901 West Main Street
Freehold, NJ 07728
HOTLINE: (732) 294-2595

Jersey Shore University Medical Center AES
1945 Route 33
Neptune, NJ 07753
HOTLINE: (732) 776-4555

Riverview Medical Center AES
1 Riverview Plaza
Red Bank, NJ 07701
HOTLINE: (732) 219-5325

Morris County

Prime Healthcare Services, St. Clare's LLC
25 Pocono Road
Denville, NJ 07834
HOTLINE: (973) 625-6160

Morristown Memorial Hospital AES
100 Madison Avenue
Morristown, NJ 07960
HOTLINE: (973) 540-0100

Chilton Memorial Hospital AES
97 West Parkway
Pompton Plains, NJ
07444 HOTLINE: (973)
831-5078

Ocean County

Monmouth Medical Center (PESS)
600 River Avenue, Lakewood, NJ 08701
HOTLINE: (866) 904-4474 or
(732) 886-4474

Passaic County

St. Joseph's Hospital Health Care
System
703 Main Street
Paterson, NJ 07503
HOTLINE: (973) 754-2230

Salem County

Healthcare Commons, Inc.
@ Salem Medical center
310 Woodstown Road
Salem, NJ 08079
HOTLINE: (856) 299-3001

Somerset County

Bridgeway Rehabilitation, Inc.
282 East Main Street
Somerville, NJ 08876
HOTLINE: (908) 526-4100

Sussex County

Newton Medical Center
175 High Street
Newton, NJ 07860
HOTLINE: (973) 383-0973

Union County

Trinitas Regional
Medical Center
655 East Jersey Street
Elizabeth, NJ 07201
HOTLINE: (908) 994-7131

Overlook Medical
Center AES
99 Beauvoir Road
Summit, NJ 07206
HOTLINE: (201) 841-8078

Rahway Hospital AES
865 Stone Street
Rahway, NJ 07065
HOTLINE: (732) 381-4949/(732) 499-6165

Warren County

Family Guidance Center
of Warren County
370 Memorial Parkway
Phillipsburg, NJ 08865
HOTLINE: (908) 454-5141

**MENTAL HEALTH AND HOMELESSNESS
PREVENTION SERVICES**

Bridgeway Rehabilitation Services
265 West Grand Street, Elizabeth, NJ 07202
(908) 289-7330

Catholic Charities - Diocese of Metuchen
26 Safran Avenue, Edison, NJ 08817
(732) 738-1323

Comprehensive Behavioral Healthcare, Inc.
395 Main Street, Hackensack, NJ 07601
(201) 646-0333

East Orange General Hospital
300 Central Avenue, East Orange, NJ 07018

(973) 395-4164

Easter Seal Society of N.J.

2083 Route 57, Washington, NJ 07882
(908) 689-6600

Healthcare Commons Family

Health Services

500 Pennsville-Auburn
Road
Carney's Point, NJ
08069
(856) 299-3200

**Jewish Family Services of Atlantic
County**

607 North Jerome Ave, Margate, NJ
08402
(609) 822-1108

**Mental Health Association of Morris
County**

100 Route 46 - Bldg. C,
Mountain Lakes, NJ 07046
(973) 334-3496

Bridgeway Rehabilitation Services

93 Stickles Pond Road, Newton, NJ
07860
(973) 383-8670

Cape Counseling Services

1129 Route 9 South
Cape May Courthouse, NJ 08210
(609) 886-6200

Cumberland County Guidance Center

2038 Carmel Road Millville, NJ 08332
(856) 825-6810

Easter Seal Society of N.J.

200 Rt 31 N- Ste 115 Flemington, NJ
08822

(908) 788-7580

Jersey City Medical Center

953 Garfield Avenue – 1st Floor
Jersey City, NJ 07304
(201) 915-2980

Legacy Treatment Services

1289 Rt 38, Ste 200, Hainesport, NJ 08036
(609) 261-7672, ext. 3201

**Mental Health Association
of Monmouth County**

119 Ave @ the Commons - Suite 5
Shrewsbury, NJ 07701
(732) 542-6422

New Point Behavioral Health

1070 Main Street, Sewell, NJ 08080
(856) 256-3320

Oaks Integrated Care

499 Cooper Landing Rd
Cherry Hill, NJ 08034
(856) 428-1300

Project Live, Inc.

465-475 Broadway, Newark, NJ 07104
(973) 481-1211

Richard Hall CMHC Project

500 North Bridge St.
Bridgewater, NJ 08807
(908) 253-3128

St. Joseph's Regional Medical Center

645 Main St – 2nd Fl
Paterson, NJ 07503 (973) 754-4781

Oaks Integrated Care

31 Lexington Avenue, Ewing, NJ 08618

(609) 583-1900

Ocean Mental Health Services, Inc.

687 Route 9, Bayville, NJ 08721
(732) 269-4849

Preferred Behavioral Health of NJ

725 Airport Rd - CN 2036,
Lakewood, NJ 08701
(732) 367-2665

**South Jersey Behavioral Health
Resources, Inc.**

400 Market Street, Camden, NJ 08102
(856) 361-2700

**Rutgers University Behavioral Health
Care**

151 Centennial Ave, Piscataway, NJ
08855
(732) 235-6184

SUPPORT GROUPS

Northern NJ

Participants: Mixed Group
2nd Thursday of every month
Phone: 201-874-9264
Email: finewine@ptd.net

North Central NJ

Participants: Caregivers
Hartwyck @ Cedar Brook
Facilitator: Christine Hogan, LCSW
Phone: 732-235-5993
Hoganch1@rutgers.edu

Central NJ

Participants: Mixed Group
Call for information:
Judy Rokeach, RN
732-235-5993
jar464@rwjms.rutgers.edu

Southern NJ

Meets 1st Wednesday of every month
Facilitator: Nancy Alterman, LCSW
856-566-7078 or 856-669-4626
alternmn@rowan.edu

Meets 3rd Wednesday of the month
Facilitator: Bob Sylvia
617-504-8593 or bobsylvia1948@gmail.com

**NURSING HOMES WITH DEDICATED HD
UNITS**

Hartwyck at Cedar Brook

1340 Park Ave., Plainfield, NJ 07060
908-754-3100
Contact is Karen Petrin

Leisure Chateau Rehabilitation

962 River Avenue, Lakewood, J 08701
732-370-8600
Contact is Judy Cerciello

**Online Support Groups offered by
HDSA**

Online Groups:

- HD Positive, Early Symptoms
- Parent Caregiver
- Caregiver Support Group
- At Risk/Not Tested
- Youth Support Group
- Family Planning

https://www.supportgroupscentral.com/groups_detail.cfm?cid=27&CFID=1718460&CF_TOKEN=2798f4db35009285-8E83EF16-F52E-E414-A1B1FEEF5A9D7A64

HD COUNSELING SUPPORT

<https://hdsa.org/find-help/community-social-support/hdsa-telehealth/>

For families affected by HD, every family member can receive counseling with up to 8 telehealth visits per year.

SOCIAL CLUBS

The Social Scene:

A Club for Adults with Special Needs

- Virtual E-Social Scene offered

Members can:

Socialize, exercise, learn life skills, and be active in their community

www.thesocialsceneclub.com

thesocialscenenj@gmail.com

201-241-0476

Easterseals of New Jersey

25 Kennedy Blvd., Suite

600 East Brunswick, NJ

08816 732-257-6662

Creates life-changing solutions for individuals with disabilities and their families in their community by increasing independence, maximizing opportunities, minimizing barriers and enhancing quality of life.

HDSA NJ CENTER OF EXCELLENCE SPECIALIZING IN HD CARE:

HDSA Center of Excellence at Rutgers University and Rowan University

42 East Laurel Road

Rowan University-School of Osteopathic Medicine

Department of Pathology-Huntington Disease Center

Stratford, NJ 08084

Phone: 732-235-5993

OTHER CENTERS SPECIALIZING IN HD CARE

NEAR NJ

HDSA Center of Excellence at University of Pennsylvania HD Center

Parkinson's Disease and Movement Disorders Center

330 South 9th Street Philadelphia, PA 19107

Phone: 215-829-5176

Website: <http://www.uphs.upenn.edu/neuro/>

HDSA Center of Excellence at Columbia University/NYS Psychiatric Institute

1051 Riverside Drive New York, NY 10032

Phone: 212-305-4597

Website: <http://hdny.org/>

HDSA Center of Excellence for Huntington's Disease at Johns Hopkins

Meyer 2-181

600 N. Wolfe Street

Baltimore, MD 21287

Phone: 410-955-2497

Website:

https://www.hopkinsmedicine.org/psychiatry/specialty_areas/huntingtons_disease/

INDEPENDENT NJ PHYSICIANS TREATING HD

Amy Colcher, MD

Movement Disorder Specialist

Cooper Neurological Institute

856-546-8525

Andrew McGarry, MD

Movement Disorder Specialist

Cooper Neurological Institute

856-546-8525

Anjali Patel, DO

Movement Disorders

Atlantic Neuroscience Institute

908-522-2829

Fiona Gupta, MD
Movement Disorder Specialist North
Jersey
Brain & Spine Center
201-342-2550

Jia Zhen Cheng, MD
Movement Disorder Specialist
CentraState Medical Center
Phone: 732-431-2000

**Marcie Rabin,
MD** Movement
Disorders
Atlantic Neuroscience
Institute 908-522-2829

Roger Kurlan, MD
Movement Disorder Specialist
The Cognitive and Research Center
973-850-4622

**ELDER CARE/DISABILITY
ATTORNEYS**

Allison Bartlett, Esq.
HDSA Manager of Disability Programs
abartlett@hdsa.org
(212)242-1968

**Suzanne M. Carter,
Esq.** 7612 Bergenline
Ave North Bergen, NJ
07047
(877) 706-3335

**Doug Fendrick &
Jamie Morgan**
1307 White Horse
Road Bldg. B, Suite
200 Voorhees, NJ
08043
(856) 489-8388

Dana Bookbinder, LLC
8000 Sagemore Drive, Suite
8303, Marlton, NJ 08053
(856) 722-8500

**Scott Counsel Elder Law
Attorneys**
1230 Brace Road
Cherry Hill, NJ 08034
(856) 281-3131

Richard M. Cohen, Esq
2090 East Route 70 Cherry
Hill, NJ 08003
(856) 616-0757

**Robert J. Keltos, Esq
Rothamel Law**
525 Route 73 North, Suite
104,
Marlton, NJ 08053
(856) 795-3400

Daniel Del Collo, III
309 Fellowship Road,
Suite 200
Mount Laurel, NJ 08054
(856) 533-2405

**Bratton Estate & Elder Care
Attorneys**
18 Kings Hwy West
Haddonfield, NJ 08033
(856) 517-0239

Poserina & McHugh
1029 South Route 9
Cape May Court House, NJ
08210
(609) 463-8125

Michael A Manna & Associates
66 South Maple Avenue
Ridgewood, NJ 07450

(866) 678-0459

Donald D. Vanarelli, Esq

242 St. Paul Street
Westfield, NJ 07090
(908) 232-7400

Witman Stadtmauer, PA

26 Columbia Turnpike, Suite 100
Florham Park, NJ 07932
(973) 822-0220

James DeMartino Elder

Law

PO Box 126
Belvidere, NJ 07823
(908) 874-5636

DRIVING EVALUATIONS

**Bacharach Institute for
Rehabilitation**

61 West Jimmie Leeds Road
Pomona, NJ 08240
Contact: Claire McLaughlin, OTR,
CDRS
Phone: (609) 748-6866
Fax: (609) 652-9581
<https://www.bacharach.org/services/driving-program/>

Kessler Institute for Rehabilitation

300 Market Street
Saddle Brook, NJ 07663
Contact: Beth Rolland, OTR, CDRS
Phone: (201) 368-6072
Fax: (201) 368-6075
<https://www.kessler-rehab.com/conditions-and-services/neurologic-rehabilitation/>

Kessler Institute for Rehabilitation

1199 Pleasant Valley Way
West Orange, NJ 07052
Contact: Rich Nead, CDRS
or David Massler, COTA, DRS
Phone: (973) 731-3900 x2322
Fax: (973) 243-6842
<https://www.kessler-rehab.com/conditions-and-services/neurologic-rehabilitation/>

**JFK Johnson Rehabilitation Institute at JFK
Health System**

65 James Street
P.O. Box 3059
Edison, NJ 08818-3059
Contact: Katie J. Hutzayluk, MS OTR/L, CDRS or
Brigitte A. Muehlbauer, MS OTR/L, CDRS
Phone: (732) 321-7056
Fax: (732) 205-1463
<https://jfkjohnson.org/outpatient-services/occupational-therapy/>

St. Lawrence Rehabilitation Center 2381

Lawrenceville Road
Lawrenceville, NJ 08648
Contact: Carrie Monagle, OTR, CDRS Phone:
(609) 896-9500 x2494
Fax: (609) 896-0698
www.slrc.org

Moss Rehab Driving School

201 Old York Road Jenkintown, PA 19046
Contact: Dan Basore, CDRS
or Lynne Mason, OTR, CDRS
Phone: (215) 886-7706
Fax: (215) 886-7709
<https://www.mossrehab.com/driving>

SWALLOW STUDIES

Hackensack Meridian Health

360 Essex Street, Suite 202
Hackensack, NJ 07601
551-996-3830

Moss Rehab at Woodbury

135 S. Broad St
Woodbury, NJ 08096
856-853-9900

The Valley Hospital

223 N. Van Dien Avenue
Ridgewood, NJ 07450
201-447-8000

Cooper University Hospital Speech and Language Services

3 Cooper Plaza, Suite 511 Camden, NJ
856-342-3060

Mobile Dysphagia Imaging

3 Chandler Ter, Rockaway, NJ 07866
973-814-4066

Overlook Medical Center

99 Beauvoir Avenue, Summit, NJ 07901
908-522-2000

Morristown Medical Center

100 Madison Avenue
Morristown, NJ 07960
973-971-5000

Newton Medical Center

175 High Street, Newton, NJ 07860
973-383-2121

Chilton Medical Center

97 West Parkway Pompton Plains, NJ

07444 973-831-5000

RWJ University Hospital New Brunswick

1 Robert Wood Johnson Place
New Brunswick, NJ 08901
908-685-2946

Saint Clare's Denville Hospital

25 Pocono Road, Denville, NJ 07834
973-625-6000

Inspira Rehab Care

Bridgeton Health Center
333 Irving Avenue
Bridgeton, NJ 08302
856-575-4585

COOKBOOKS AND NUTRITION

“Pass the Calories, Please”

By F. Gail

“The Non-Chew Cookbook”

By J. Randy Wilson

“Easy to Swallow, Easy to Chew”

By Donna L. Weihofen

“Soft Foods for Easier Eating Cookbook”

By Sandra Woodruff

“The Dysphagia Cookbook”

By Todd Levine, MD

“The I Can't Chew Cookbook”

By J. Randi Wilson

LOW COST/FREE MEDICAL EQUIPMENT

Good Will Home Medical

300 Benigno Boulevard
Bellmawr, NJ 08031
609-812-2210

Monday through Friday: 9:00am – 3:00pm
Saturday: 9:00am – 1:00pm

<https://www.goodwillhomemedical.org/>

Trinity Church

211 Main Street
Hackettstown, NJ 07840

908-852-3020

Main St. Store Hours:
Tuesday – Saturday
10:00 am – 3:00 pm

Loans wheelchairs and other medical equipment at no charge...family just returns it when no longer needed.

<https://www.catchthespirit.org/>

DISABILITY QUESTIONS ANSWERED

Allison Bartlett, Esq.

HDSA Manager of Disability Programs
abartlett@hdsa.org
(212)242-1968

<https://hdsa.org/find-help/healthcare-and-future-planning/disability-benefits-and-hd-2/>

<https://www.ssa.gov/benefits/disability/>

HELP WITH LONG TERM MEDICAID (MLTSS)

Elder Guide
7 Randolph Road

Howell, NJ 07731
Phone: (908) 212-1691
Fax: (908) 548-0867
info@elderguide.net

They collect and review the necessary documents for a Medicaid application, and handling all correspondences with the Board of Social Services until the approval is obtained.

<https://elderguide.net>

Aging & Disability Resource Connection/Area Agency on Aging (ADRC/AAA)

1-877-222-3737

<https://www.state.nj.us/humanservices/doas/home/saaaa.html>

HELP WITH MEDICARE PLANS

State Health Insurance Assistance Program (SHIP)

1-800-792-8820

The State Health Insurance Assistance Program (SHIP) provides free help to New Jersey Medicare beneficiaries who have problems with, or questions about their health insurance.

PREIMPLANTATION GENETIC DIAGNOSIS (PGD) & GENETIC COUNSELING

**Robert Wood Johnson Medical School
Department of OB/GYN**

Division of Maternal- Fetal Medicine
Section of Perinatal Genetics

125 Paterson St- CAB 2151
New Brunswick, NJ 08901
732-235-6630

**Reproductive Science
Center of New Jersey-**
Eatontown, Toms River,
Lawrenceville

1-877-487-3447

**Find a Genetic
Counselor**

<https://www.findageneticcounselor.com/>

(312) 321-6834

HDSA

<https://hdsa.org/what-is-hd/history-and-genetics-of-huntingtons-disease/genetic-testing-family-planning/>

HELP WITH MEDICATIONS

Generic Tetrabenazine

TAGI Pharma Customer Service
1-855-225-8244

Austedo

Teva Shared Solutions
1-800-887-8100
www.sharedsolutions.com

Xenazine

Lundbeck
1-888-882-6013

www.xenazineusa.com

BioTek

reMedys

Specialty Pharmacy
646-294 - 9866

www.biotekrx.com

BRAIN DONATION

**Harvard Brain Tissue Resource Center at
McLean Hospital**

1-800-BRAIN BANK or 617-855-2400

<http://mcleanhospital.org/hbtrc/>

Massachusetts General Hospital

**HDSA supported brain bank through
MGH**

The 24-hour contact number is

617-724-5700

Page #21300

HD RELATED FINANCIAL ASSISTANCE

HealthWell

Disease Funds: Grant applications for chronic or life-altering diseases, that provides support for prescription copays, health insurance premiums, deductibles, and coinsurance, and travel costs.

<https://www.healthwellfoundation.org/fund/huntingtons-disease-medicare-access/>

NORD

Provides assistance programs to help patients obtain life-saving or life-sustaining medication, and financial assistance with insurance premiums and copays, diagnostic testing assistance, and travel assistance for clinical trials.

<https://rarediseases.org/wp->

[content/uploads/2020/11/Chorea-PAP-FAQ-10-2020.pdf](https://www.patientservicesinc.org/content/uploads/2020/11/Chorea-PAP-FAQ-10-2020.pdf)

Patient Services

Financial support and guidance for patients with chronic diseases.

<https://www.patientservicesinc.org/>

THERAPY FOR INDIVIDUALS WITH HD

Occupational Therapy:

OTs help people across the lifespan do the things they want, need, and are expected to do through the therapeutic use of daily activities (occupations), and aim to solve problems and barriers that may interfere. OTs assist with ADLs (Self-care, Dressing, Feeding), IADLS (Home and Medication Management), Play, Education, Sleep, Work, Leisure, and Social Participation. (AOTA)

<https://www.njota.org/find-a-therapist#/>

Physical Therapy:

PTs are movement experts who diagnose and treat individuals of all ages, to improve quality of life through prescribed exercise, hands-on care, and patient education. PTs develop a treatment plan to improve a person's ability to move, reduce, or manage pain, restore function, and prevent disability. (APTA)

<https://aptaapps.apta.org//APTAPTDiretory/FindAPTDiretory.aspx>

Speech-Language-Hearing Pathologist:

SLPs work with people of all ages to treat communication and swallowing problems such as speech sounds, language, literacy, social

communication, voice, fluency, cognitive-communication, and feeding and swallowing. (ASHA)

<https://www.njsha.org/member-center/#/public-search>

LONG-TERM CARE

Search for long-term care and assisted living facilities, as well as adult day programs in NJ , specifically by county:

<https://healthapps.state.nj.us/facilities/fsSearch.aspx>

Long Term Care Ombudsman (NJLTCO)

Responsible for securing, preserving, and promoting the health, safety, and welfare of NJs elderly population, through investigations of abuse, neglect, and exploitation; legislative and regulatory advocacy; policy work; and education and outreach.

Phone: 877-582-6995

<https://www.state.nj.us/ooie/>

Aging & Disability Resource Connection NJ

Visible and trusted source of information on long-term services and supports for persons of all incomes. ADRC assists and empowers seniors, adults, and their caregivers to make informed decisions, and in finding benefits and services they need such

Phone: 877-222-3737

<https://adrcnj.org/find-services-and-provider>

HOME SAFETY EVALUATIONS

Fox Rehab

877-407-3422

<https://www.foxrehab.org/>

SOS Group

856-740-4000

<https://www.sosgroup.info/>

Back Home Safely

973-219-4147

<https://backhomesafely.com/>

HD YOUTH

HDSA National Youth Alliance

<https://nya.hdsa.org/>

Motivates youth to get involved in their local HDSA Chapters, Affiliates, and Support Groups in efforts through education, fundraising, advocacy and awareness for Huntington's disease. The NYA is a collection of children, teens and young adults from across the country.

Huntington's Disease Youth Organization (HDYO)

<https://en.hdyo.org/>

A non-profit set up to provide support and education to young people impacted by HD around the world. HDYO provides support and education, creates education content for all age groups, connect young people with peers, makes events such as youth camps and conferences, and provides opportunities for young people to get involved.

INTERNET RESOURCES

COMMUNICATING WITH HEALTHCARE PROVIDERS

<http://hdsa.org/wp-content/uploads/2015/03/Caregivers-Guide-to-Communicating-with-Healthcare-Providers.pdf>

LONG TERM CARE

<http://hdsa.org/wp-content/uploads/2015/05/long-term-care.pdf>

CAREGIVER GUIDES

<http://hdsa.org/wp-content/uploads/2015/03/A-Caregivers-Guide-to-HD.pdf>

http://hdsa.org/wp-content/uploads/2015/04/CaregiverGuide_Mid_Late_StageHD.pdf

http://hdsa.org/wp-content/uploads/2016/05/HDSA_CaregiverGuideFamilies_Final.pdf

LIFTING THE VEIL

<http://hdsa.org/wp-content/uploads/2015/03/Lifting-the-Veil-of-HD.pdf>

ADVANCE DIRECTIVES

http://hdsa.org/wp-content/uploads/2015/03/HDSA_Family-Guide-Advance-Directives-for-HD.pdf

GENETIC TESTING

<http://hdsa.org/wp-content/uploads/2015/03/GeneticTesting.pdf>

<http://hdsa.org/wp-content/uploads/2015/03/GeneticTesting-for-HD.pdf>

JUVENILE HD

http://hdsa.org/wp-content/uploads/2015/03/Juvenile-HD-Handbook_2nd-Edition.pdf

http://hdsa.org/wp-content/uploads/2015/03/JuvenileHD_School-Experience_APR2015.pdf

HD AND THE LAW

<http://hdsa.org/wp-content/uploads/2015/05/HDSA-LET-Caregivers-Guide1.pdf>

SPEECH & SWALLOWING

<http://hdsa.org/wp-content/uploads/2015/03/Speech-Language-Swallowing-Difficulties.pdf>

NUTRITION

<http://hdsa.org/wp-content/uploads/2015/04/Nutrition-and-HD.pdf>

TALKING WITH KIDS ABOUT HD

<http://hdsa.org/wp-content/uploads/2015/03/Talking-with-Kids1.pdf>

PHYSICAL AND OCCUPATIONAL THERAPY

http://hdsa.org/wp-content/uploads/2015/03/PhysicalOccupationalTherapy_FamilyGuide.pdf

<http://hdsa.org/wp-content/uploads/2015/07/When-to-Call-a-Physical-or-Occupational-Therapist-in-Huntingtons-Disease.pdf>
<https://jfkjohnson.org/outpatient-services/parkinsons-disease-program/lsvt-loud-and-loud-for-life/>

DRIVING

http://web.stanford.edu/group/hopes/cgi-bin/hopes_test/driving-and-huntingtons-disease/

HOME SAFETY

<https://www.winchesterhospital.org/health-library/article?id=21068>

BRAIN DONATION

<http://www.brainbank.mclean.org/donate/>

NJ STATE DISABILITY APPLICATION

http://lwd.dol.state.nj.us/labor/tdi/state/sp_clt_menu.html

SOCIAL SECURITY DISABILITY

<https://www.ssa.gov/disability/>

<https://hdsa.org/find-help/healthcare-and-future-planning/disability-benefits-and-hd-2/>

PSYCHIATRIC SCREENING (CRISIS CENTERS)

http://www.state.nj.us/humanservices/dmhas/home/hotlines/MH_Screening_Centers.pdf

NJ COUNTY WELFARE AGENCIES

<http://www.state.nj.us/humanservices/dfd/programs/njsnap/cwa/>

MEDICAID NJ-MLTSS

<http://www.nj.gov/humanservices/dmahs/home/mltss.html>

BEHAVIOR AND HD

http://web.stanford.edu/group/hopes/cgi-bin/hopes_test/the-behavioral-symptoms-of-huntingtons-disease/

ADULT PROTECTIVE SERVICES

<http://www.state.nj.us/humanservices/doas/documents/APS%20flyer.pdf>

CRISIS FLOW SHEET ON NEXT PAGE

Help for HD patients and families in crisis

911

1. Person is in imminent danger
2. Has intent and means to hurt self or others
3. MH crisis is severe (psychosis, emotionally unstable, etc.)

APS

- Types of elder/disabled adult abuse:
1. Physical harm or injury
 2. Neglect
 3. Financial exploitation
 4. Verbal or emotion abuse
 5. Involuntary seclusion
 6. Physical or chemical restraint
 7. Unwanted sexual contact
 8. Self-neglect (individual lacks capacity)

CPS

- Suspected or known abuse: parent or caregiver, whether through action or failing to act, causes injury, death, emotional harm or risk of serious harm to a child.
- Forms of child maltreatment:
1. Neglect
 2. Physical abuse
 3. Sexual abuse
 4. Exploitation
 5. Emotional abuse

Police Non-Emergency

1. Person in need of a welfare check
2. Reporting a crime that was already committed
3. Third party reported SI/HI or emotional instability and no one can connect with the person on the phone

ER

1. Person is willing to get help for SI/HI or emotional instability
- AND is:
2. accompanied by a responsible person

NOTES