



HDSA Presents Disability Chat with Allison Bartlett, Esq.



What You Need to Know: Preparing to File a Disability Application and Collecting Medical Records

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HDSA Disability Chat Series
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How to ask a question

- It's easy to ask a question.
- All questions will be answered after the presentation but you can send a question at any time during Allison's presentation.
- Just click on the "CHAT" function in the toolbar, type your question and hit send. Your questions cannot be seen by others – only by HDSA.
- This presentation will be available in about a week on HDSA's Youtube channel or by going to: www.hdsa.org/disabilitychat

Upcoming webinars

- **March 19: Debunking Disability Myths.** An in-depth look at common Social Security disability myths at every stage of the disability process.
- **May 21: Disability Red Flags.** What you need to know about the 6 common red flags in a disability claim and how to mediate or avoid them.
- **July 16: Completing Disability Forms (Wk Activity, ADF, Wk Hx, Pain Q, Anx Q).** An overview of what Social Security disability forms you may receive during the disability application process and how to complete them.



Huntington's Disease
Society of America

The information provided in this webinar series is for informational use only.

HDSA encourages all attendees to consult with their primary care provider, neurologist or elder care attorney about any advice mentioned as part of any presentation.

What You Need to Know: Preparing to File a Disability Application and Collecting Medical Records.

An overview of when to start preparing a disability claim, what information to gather, how to collect medical records and other evidence, and completing the application.

Overview

- Starting the Disability Process
- Gathering Evidence
- Collecting Medical Records
- Ready to File

Starting the Disability Process

- Importance of Preparation
 - Can help expedite the case
 - Can help you get approved
 - Can help you better understand and describe your symptoms and limitations
 - Can help you advocate for case with Social Security



TIP: You should have copies of your medical records and know what is written in them

Starting the Disability Process

- Common Misconceptions
 - You have to stop working to apply for disability
 - Work = earning less than \$1,260 per month
 - You have to be wait to apply for disability
 - Can apply for disability as soon as you stop working or earn less than \$1,260 per month
 - The process will only take a few months
 - National average for initial decision is 6 months
 - Decision could take 3+ years

Disability Timeline

- **5+ Years**
 - Research private insurance: Disability and Long-Term care
- **3 Years**
 - Start seeing a neurologist to create a baseline of symptoms & track HD progression
 - Make sure you are enrolled in employer provided Short Term and Long-Term disability if they are available
- **1 Year**
 - Confirm Short Term and Long-Term disability benefits with employer
 - Let neurologist know you are starting to think about applying for disability
- **6 months**
 - Start gathering evidence in the form of medical records and letters from family, friends, employers, and physicians
- **1 Month**
 - Begin planning last day of work and communicate with HR to start disability paperwork with employer, if applicable; OR
 - Begin planning when you are going to cut back hours at work to earn less than \$1,260 per month
- **Start and submit the application**



WARNING

- Should I keep working?
- Is it time to apply for disability?
- How do I know when it is the right time?

Starting the Disability Process

- Warning Signs
 - Start having issues at work
 - Inability to perform job tasks
 - Trouble interacting with coworkers and supervisors
 - Difficulty attending work and concentrating
 - Have trouble holding a job consistently
 - Unable to keep a job for more than 3 months
 - Have multiple jobs in a 12-month period
 - Have not worked in over 12 months
 - Making less than \$5500 a year (meaning you are not earning all 4 credits)

Starting the Disability Process

- First Steps
 - Familiarizing yourself with Social Security's Disability rules and regulations:
 - [Listing 11.17](#), for neurodegenerative disorders, such as Huntington's Disease
 - [Compassionate Allowance](#)
 - [Application process](#)
 - Understanding your symptoms and limitations
 - Gathering Evidence

Gathering Evidence

- **What kind of evidence do you need to gather?**
 - Medical evidence
 - Activities of Daily Living
 - Employment records
 - Education records
- **Where do you need to gather evidence from?**
 - Doctors
 - Therapists
 - Employers
 - Friends and Family
- **How do you gather evidence?**
 - Medical Records
 - Medical Letters
 - Letters from friends, families, and employers
 - Personal Experience

Activities of Daily Living

- Activities of Daily Living (ADLs) = routine activities people do every day without assistance
 - Eating
 - Getting dressed
 - Contenance
 - Bathing
 - Toileting
 - Transferring position
- Instrumental activities of daily living (IADLs) = a person's ability to live independently and thrive
 - Companionship and mental support
 - Transportation and shopping
 - Planning and preparing meals
 - Managing the household
 - Managing medications
 - Communicating with others
 - Managing finances

Activities of Daily Living

- How do you gather the evidence?
 - Keep a journal to track symptoms and limitations
 - Describe your bad days – it is very important to be able to discuss bad days with doctors and with Social Security
 - Include all changes and accommodations that you have made to your life no matter how small the changes seem
 - Write a letter to Social Security
 - Include what you want Social Security to know about your HD and how it has impacted your life
 - Writing the letter in advance gives you time to think about what you want to include and provide examples of symptoms and limitations
 - Get letters from friends and family
 - Letters should come from the people who know you best
 - Provide specific examples with dates of how HD has impacted your life from the time of symptom onset to the present

Work History & Employment Record

- **Work History**
 - Past 15 Years, month/year work started and ended
 - Ex: 11/2015 - 05/2019
 - Job title
 - Address and phone number of most recent jobs
 - Job descriptions
 - Resume
 - Day to day tasks
- **Employment Record**
 - Employment reviews
 - Disciplinary actions
- **Letters from coworkers or supervisors**
 - Changes in your ability to work
 - Job accommodations

Education Records

- Only relevant for younger individuals, under 25, and people who recently attended school
- High School
 - Individualized Education Program (IEP)
 - Special education classes
 - Accommodations provided by school
 - State test scores
- College or Trade School
 - Accommodations provided by school
 - Grades and attendance records

Medical Evidence

- Medical Records
 - Doctors/Hospitals
 - Neurologist
 - Primary Care Physician
 - Psychiatrist/Psychologist
 - Physical therapy
 - Occupational therapy
 - Prisons and correctional facilities
 - Welfare agencies
 - Insurance companies who have paid disability benefits
- Medical Letters
 - You should get letters from your specialists, most importantly your neurologist and treating psychiatrist (if applicable)
 - The letter needs to specify your symptoms and limitations and how they prevent you from working, your doctor stating you are disabled without proof is not enough and Social Security DOES NOT like it

Collecting Medical Records

- Medical records are ESSENTIAL for your claim
 - You cannot and will not be found disabled without medical records
 - Medically determinable impairment
- Collecting medical records can be complicated and time consuming
 - It can be a multi-step process
 - Can take weeks to receive records
 - It is very important for you to have copies of all of your records
- Do not rely on Social Security to collect medical records for your claim
 - Social Security will only follow up on medical record requests a limited number of times – if they do not get important records, they still have to make a decision on your claim
 - Social Security may send record request to the wrong facility
 - HDSA Center of Excellence at Columbia University/NYS Psychiatric Institute
 - Samuel L. Baily Huntington's Disease Family Service Center at Rutgers

How to Obtain Medical Records

- Patient portal
 - Download directly from patient portal, this is always free
 - Request records through patient portal
- Doctors
 - Ask doctors/social worker for copies of medical records or how to obtain records
- Medical record department
 - Go to hospital medical record department in person and request records
 - Email or fax request to medical record department

How to Submit a Request

- Online - through patient portal
- Release of Medical Information
 - Completing
 - Make sure to include dates of service, it is better to overestimate
 - Make sure to request records from correct facility – better to check multiple facilities if you are not sure
 - Medical Information
 - Consultations/evaluations
 - Outpatient reports
 - Progress notes
 - Diagnostic imaging report
 - Submitting Release
 - Visit medical record department in person
 - Fax or email release

Medical Record Request

If you are currently accessing another patient's chart, this will be a request for their medical record, not yours.
All fields are required.

After completing this request, you can expect a response through MyChart within 14 business days.

Requests for medical records cannot always be fulfilled through MyChart because the documentation resides in another electronic medical record outside of Epic.

Records are available through MyChart for visit dates after:

MyChart Visit Date Reference Guide		
Service Location	for Dates of Service After:	
Centegra Physician Care	May	2019
Central DuPage Hospital	November	2011
Delnor Hospital	November	2012
KishHealth Physician Group	May	2017
Kishwaukee Hospital	May	2017
Lake Forest Hospital	March	2018
Marianjoy Medical Group	September	2019
Marianjoy Rehabilitation Hospital	September	2019
Northwestern Memorial Hospital	March	2018
Northwestern Medical Group	March	2018
Northwestern Medicine Regional Medical Group	November	2011
Valley West Hospital	May	2017

For visit dates prior to the dates listed above:

Please visit NM.org to obtain an authorization form and instructions on how to submit your request.

Type of Records (your choices are):

Key Clinical Documentation (includes provider notes such as emergency department report, history and physical, discharge summary, office notes, consultation, operative report, testing reports, and lab reports)

All Clinical Documentation (includes records listed in the Key Clinical Documentation plus physician orders, progress notes, nursing notes, medication administration record, etc.)

Requester Information

Please supply contact information in case we have questions regarding your request.

Please reference the MyChart Visit Date Reference Guide (see above) for visit dates available through MyChart.

Phone number:

Information requested:

Approximate service date range start:

Approximate service date range end:



Northwestern Medicine
 Attn: Medical Records
 25 North Winfield Road
 Winfield, Illinois 60190
 877.9RECORD Phone
 (877.973.2673)
 312.926.3093 Fax
 releaseofinformation@nm.org

AUTHORIZATION FOR RELEASE OF MEDICAL INFORMATION

Patient medical information will be released upon receipt of valid authorization.
 Please tell us where you received your treatment by placing an (X) next to the location.

- | | |
|---|--|
| <input type="checkbox"/> Northwestern Memorial Hospital | <input type="checkbox"/> KishHealth System Physician Group |
| <input type="checkbox"/> NM Marianjoy Rehabilitation Hospital | <input type="checkbox"/> Marianjoy Medical Group |
| <input type="checkbox"/> NM Lake Forest Hospital | <input type="checkbox"/> NM Kishwaukee Hospital |
| <input type="checkbox"/> NM Lake Forest Hospital-Grayslake | <input type="checkbox"/> NM KishHealth Ben Gordon Center |
| <input type="checkbox"/> NM Central DuPage Hospital | <input type="checkbox"/> NM KishHealth Cancer Center |
| <input type="checkbox"/> NM Delnor Hospital | <input type="checkbox"/> NM Cancer Center - Warrenville |
| <input type="checkbox"/> NM Valley West Hospital | <input type="checkbox"/> NM Cancer Center - Geneva |
| <input type="checkbox"/> NM Proton Center | <input type="checkbox"/> Regional Medical Group |
| <input type="checkbox"/> Northwestern Medical Group | |

_____	/ /
Patient Name	Date of Birth
_____	() -
Address	Phone number
_____	_____
City	State Zip Code

I authorize Northwestern Memorial HealthCare ("NMHC") and its clinical affiliates to release information to the following party at the below address:

_____	_____	_____
Name (Example: Health Care Facility, Insurance Co., Attorney, Self)	Phone Number	Fax Number
_____	_____	_____
Street Address	City	State Zip Code

Purpose:
 Future Treatment Personal Use Insurance Attorney/Client Other (specify) _____

- Requested Medical Information:**
- | | | | |
|--|---|--|---|
| <input type="checkbox"/> Inpatient Record Abstract | <input type="checkbox"/> Outpatient Record Abstract | <input type="checkbox"/> ED Report | <input type="checkbox"/> History and Physical |
| <input type="checkbox"/> Consultation Report | <input type="checkbox"/> Operative Report | <input type="checkbox"/> Discharge Summary | <input type="checkbox"/> Progress/Physician Notes |
| <input type="checkbox"/> Diagnostic Images | <input type="checkbox"/> Diagnostic Imaging Report | <input type="checkbox"/> Laboratory Report | <input type="checkbox"/> Immunization Record |
| <input type="checkbox"/> Films/Slides | | | |

Records for the period (dates) from _____ to _____
 Unless specifically requested otherwise, NMHC will only release the last ten (10) years of your medical records.

Additional Information (Example: physician name, specific test/result)

PLEASE NOTE YOUR RECORD PREFERENCES:

<input type="checkbox"/> Mail records (please provide mailing address in the designated area on the first page of this form)	Requested format:
<input type="checkbox"/> Fax records (please provide fax number in the designated area on the first page of this form)	
<input type="checkbox"/> Hold for pick up at:	<input type="checkbox"/> Paper
<input type="checkbox"/> Northwestern Memorial Hospital	<input type="checkbox"/> Electronic (CD)
<input type="checkbox"/> NM Central DuPage Hospital	
<input type="checkbox"/> NM Delnor Hospital	
<input type="checkbox"/> NM Lake Forest Hospital	
<input type="checkbox"/> NM Marian Joy Rehabilitation Hospital	
<input type="checkbox"/> NM Valley West Hospital	
<input type="checkbox"/> NM Kishwaukee Hospital	

Unless checked or listed below, I understand the released information may include the following information. Check and/or list if you do NOT want to include:

<input type="checkbox"/> AIDS or HIV testing information or test results	<input type="checkbox"/> Sexually Transmitted Infections (if minor)
<input type="checkbox"/> Substance abuse/Alcohol treatment	<input type="checkbox"/> Sexual Assault/Abuse (if minor)
<input type="checkbox"/> Genetic testing and/or genetic counseling records	<input type="checkbox"/> Child Abuse/Neglect (if minor)
<input type="checkbox"/> Mental health and developmental disability records	<input type="checkbox"/> Pregnancy (if minor)
<input type="checkbox"/> Other (specify) _____	<input type="checkbox"/> Birth Control (if minor)

Once the organization or person authorized to receive this information has received it, the information may be re-released by that organization or person. If this is the case, the information may no longer be protected by federal privacy laws; however, Illinois law does not allow the re-release of AIDS/HIV, genetic testing, mental health and developmental disabilities information by the receivers of the information except in precise situations allowed by law. Also, Federal Confidentiality Rules, 42 CFR Part 2, prohibit making any further disclosure of drug and alcohol information unless further disclosure of this information is expressly permitted by the written consent of the person to whom it pertains or as otherwise permitted by 42 CFR.

I understand that if I do not sign this authorization, NMHC clinical affiliates may not deny me care based on my unwillingness to sign this form; however, NMHC clinical affiliates may refuse to provide care to me if the care is being provided solely for the purpose of collecting health information to be released to a third party (for example, pre-employment exams).

I have the right to withdraw this authorization at any time. My withdrawal must be in writing. Any withdrawal will be valid except for the release of information that occurred prior to this authorization being withdrawn. For information on how to withdraw this authorization, contact NMHC Health Information Management Department at 312.926.3376.

I understand that I have the right to inspect and copy the mental health and developmental disabilities records that will be released.

If not withdrawn, this authorization is valid for a period of six (6) months from the date of signature. Standard record copying fees per 735 ILCS 5/8-2006 may apply. **By signing below I agree to the statements in this authorization form.**

Time	Date	Patient Name/Signature for patients age 12 or over			
_____	_____	_____			
Time	Date	Parent	Guardian	Legal Representative	Signature of (circle one)
_____	_____	_____	_____	_____	_____
Time	Date	Witness/Signature			
_____	_____	_____			



AUTHORIZATION FOR RELEASE OF (PHI) PROTECTED HEALTH INFORMATION

Medical Record Number: _____
 Patient Name: _____
 Birth Date: _____
 SSN (Last Four Digits – Only): _____

I authorize _____ to release PHI to: _____
 (name of person/ facility which has information)
 Name of person/ facility to receive PHI: _____

 Address: _____
 City, State & Zip Code: _____

I would like to: request a **PAPER** copy **-OR-** request an **ELECTRONIC** copy (CD)

SPECIFY HEALTHCARE FACILITY FROM WHICH PHI IS REQUESTED

<input type="checkbox"/> Ronald Reagan UCLA Medical Center	<input type="checkbox"/> UCLA Medical Center Santa Monica
<input type="checkbox"/> Resnick Neuropsychiatric Hospital	<input type="checkbox"/> Semel Neuropsychiatric Institute
<input type="checkbox"/> Home Health	<input type="checkbox"/> Jules Stein Eye Institute
<input type="checkbox"/> Clinic _____ (Specify Name of Clinic)	

TYPE OF RECORDS

MEDICAL MENTAL HEALTH (other than psychotherapy notes)

Information to be RELEASED

<input type="checkbox"/> Discharge Summary	<input type="checkbox"/> Laboratory Reports	<input type="checkbox"/> Emergency Medicine Reports
<input type="checkbox"/> Billing Statements	<input type="checkbox"/> Dental Records	<input type="checkbox"/> History & Physical Exams
<input type="checkbox"/> Pathology Reports	<input type="checkbox"/> Operative Reports	<input type="checkbox"/> Radiology & other Diagnostic Reports
<input type="checkbox"/> EKG	<input type="checkbox"/> Radiology & other Diagnostic Images (x-rays, etc.)	<input type="checkbox"/> Consultations/Evaluations
<input type="checkbox"/> Progress Notes	<input type="checkbox"/> Outpatient Clinic Records	<input type="checkbox"/> Genetic Testing Information
<input type="checkbox"/> Drug & Alcohol Abuse Information		<input type="checkbox"/> Psychological/Vocational Test Results
		<input type="checkbox"/> HIV/AIDS Test Results
		<input type="checkbox"/> HIV/AIDS Treatment Information
<input type="checkbox"/> Other _____		

SPECIFY DATE/ TIME PERIOD FOR INFORMATION SELECTED ABOVE: _____

THE PURPOSE OF THIS RELEASE IS (check one or more)

At the request of the patient/patient representative
 Other (state reason) _____

Initials of Patient or Legal Representative: _____

AUTHORIZATION FOR RELEASE OF (PHI) PROTECTED HEALTH INFORMATION

Medical Record Number: _____
 Patient Name: _____
 Birth Date: _____
 SSN (Last Four Digits – Only): _____

NOTICE

UCLA Health System and many other organizations and individuals such as physicians, hospitals and health plans are required by law to keep your PHI confidential. If you have authorized the disclosure of your PHI to someone who is not legally required to keep it confidential, it may no longer be protected by state or federal confidentiality laws.

MY RIGHTS

- I understand this authorization is voluntary. Treatment, payment enrollment or eligibility for benefits may not be conditioned on signing this authorization except if the authorization is for: 1) conducting research-related treatment, 2) to obtain information in connection with eligibility or enrollment in a health plan, 3) to determine an entity's obligation to pay a claim, or 4) to create PHI to provide to a third party.
- I may revoke this authorization at any time, provided that I do so in writing and submit it to the Health Information Management Services, UCLA Health System, 10833 Le Conte Avenue, CHS BH-225, Los Angeles, CA 90095-7305. The revocation will take effect when UCLA Health System receives it, except to the extent that UCLA Health System or others have already relied on it.
- I am entitled to receive a copy of this Authorization.

EXPIRATION OF AUTHORIZATION

Unless otherwise revoked, this Authorization expires _____ (insert applicable date or event). If no date is indicated, this Authorization will expire 12 months after the date of signing this form.

SIGNATURE

 Date: _____ Time: _____ AM / PM
 (Signature of Patient / Legal Representative)

Printed Name _____ Phone Number (Include Area Code) _____

(If signed by someone other than the patient, indicate relationship to the patient)

 Date: _____ Time: _____ AM / PM
 Signature of Witness/ Interpreter (only if patient unable to sign)

UCLA HIMS, Release of Information
 10833 Le Conte Ave, CHS BH225
 Los Angeles, CA. 90095-78305
 Fax: (310) 983-1468 Phone: (310) 825-6021

Following up on Requests

- It is very important to follow-up on requests to make sure the requests are received and processed
 - Every medical record department has a phone number to call
 - If you are not able to speak with someone, leave a DETAILED message with your name, date of birth, the date you submitted the request, and your phone number
 - When calling make sure to have date of birth and date you submitted request
 - Take notes, get the name of who you spoke with, and what action was taken
- General Rule: follow-up once per week until records are received
 - If your request is received and processing takes up to 18 or 30 days, it is okay if you do not call every week

Medical Record Costs

- Medical records can be very expensive
- In a number of states, a patient is entitled to a free copy of their medical records if the records are for disability or another public benefit program
 - California ([Health and Safety Code Section 123110\(b\)](#))
 - New York (<https://www.nysenate.gov/legislation/laws/PBH/17>)
- Each state has different laws regarding medical record costs
 - Fees range from \$0.25 per page to \$2.00 per page
 - Most states allow for a search fee that range from \$15-\$30
 - When requesting records, it might be beneficial to include a copy of the state law with the request if the records should be free
 - Don't assume the medical record processing facilities know the law
 - Be prepared to work with the medical record facility to lower the cost of the records, if necessary
- Reduce costs by only requesting what you need
 - Clinic Notes
 - Hospital admission and discharge notes

Ready to File

- Wait to file until you have gathered as much evidence as possible – bare minimum HD medical records
- You have stopped working/make less than \$1,260 per month
- Keep all evidence in one place so it is easy to find information once you start the application
- Do not rush through the application

How to File an Application

- In-person
 - Go to Social Security and complete application with a representative in one sitting, takes a few hours
 - Best for people who have gathered lots of evidence and want to confirm it is submitted with claim
- Online
 - Complete online application on own, can re-enter application and take up to 3 months to complete
 - Best for people who live far away from a Social Security Field Office and those helping someone complete the application
- Phone
 - Complete the application over the phone with a Social Security representative, takes a few hours
 - Least amount of control over what is submitted in application

What to Include in the Application

- Adult onset Huntington's disease per Listing 11.17
 - Symptoms you experience
 - Limitations caused by symptoms
- Compassionate allowance – DI 23022.923
- Marriage, prior marriage, and children
 - Spouse info: name, DOB, SSN
 - Date and location of marriage/divorce
- Past 15 years of Work History
 - Employer name and address
 - Dates of employment
 - Job details (pay, days/hours per week, physical job tasks)
- Total earnings for past 2 years
- All physical and mental conditions
- All doctors
 - Contact information: phone, address, fax number
 - First appointment/Last appointment/Upcoming appointment
 - Medical tests and Medications

What to Submit with the Application

- Personal records
 - Medical Evidence
 - Medical Records
 - Medical Letters
 - Employment Records
 - Education Records
 - Activities of Daily Living in the form of Letters
 - This information should also be included in the body of the application
 - Earnings and pay stubs if you are still working
- Social Security Forms
 - SSA1696: Appointment of Representative
 - SSA821: Work Activity Report

How to Submit Evidence

- In Person – at the Social Security Field Office
 - Submit when completing application with Social Security representative
 - Drop off after completing online application, make sure to you get a date stamped copy of your evidence as confirmation
- Mailing the Evidence
 - If you submit the application online, you will have the option to print a cover sheet in order to submit your evidence to Social Security – PRINT THE COVER SHEET and mail evidence to local Field Office
- Faxing the Evidence
 - Contact your local Social Security office and ask for the fax number to submit records via fax, also include the cover sheet

Best Practices

- Do not undermine your symptoms and limitations – do not make it seem you are better than you are
- Ask for help if you need help – this is not something that should be completed alone
- Ask questions if you have questions – this is not an easy process
- Work with your doctors and social workers throughout this process, keep them informed
- Track all doctor's appointments and contact information in a journal or a spreadsheet
- Keep an up to date list of your medications and why you take them
- Follow-up with Social Security regularly once you have submitted your application
 - Confirm application is received
 - Confirm when application is sent from Field Office to Disability Determination Services
 - Confirm Social Security gets your medical records, ESPECIALLY the HD medical records

Questions?

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www.hdsa.org