




1


 **WHY?** | Why is it important to assess swallowing in PD?

 **HOW?** | Learn what to notice  
Define how to report it to your Dr  
Understand how families can help

2



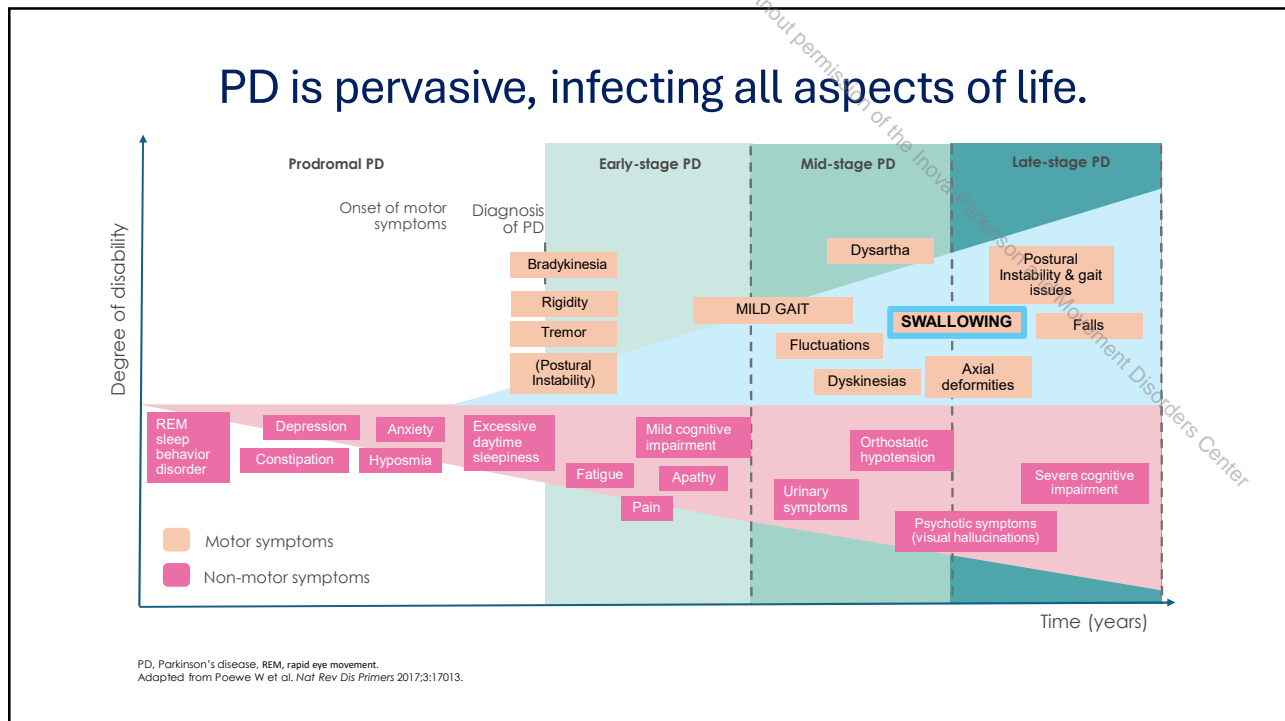
## WHY? | Why is it important to assess swallowing in PD?



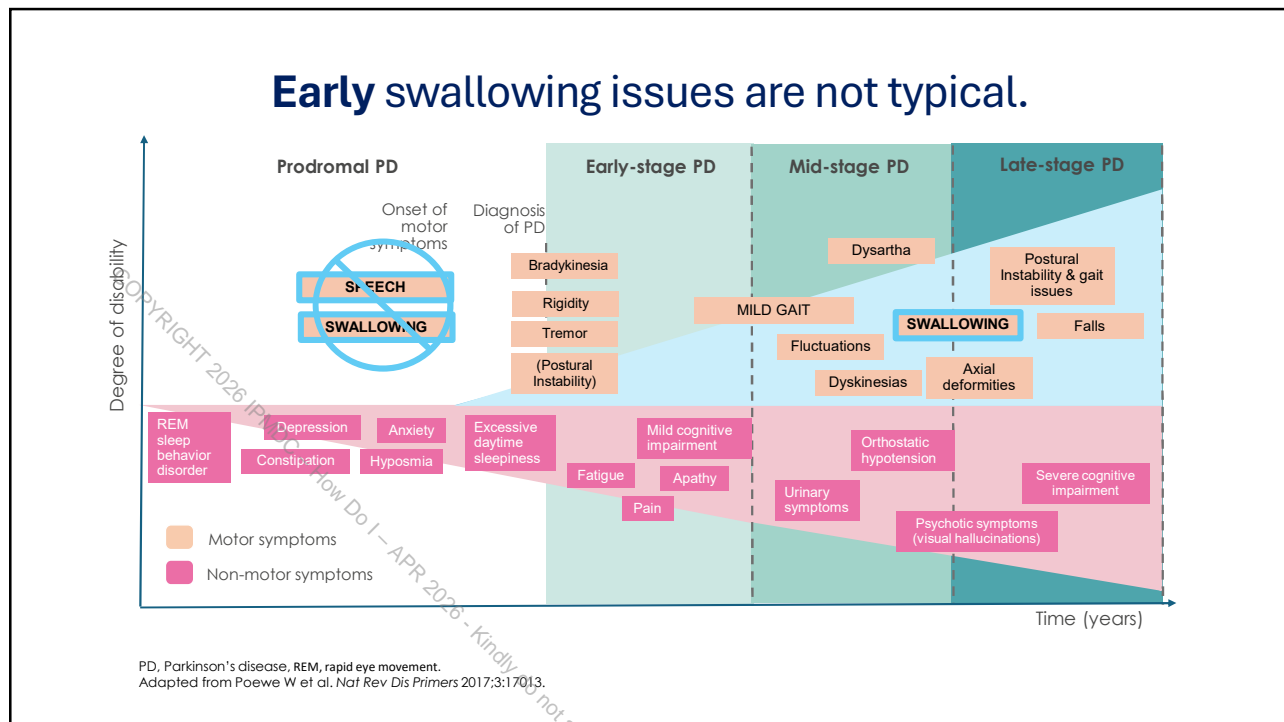
## HOW?

- Define what to notice
- Define how to report it to your Dr
- Define how can families help

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## But swallowing dysfunction may occur earlier

- Often in the prodromal or early stages  
(Martell et al., 2024)
- It's frequently unrecognized  
(due to silent aspiration)  
(Rudisch et al., 2023)

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## Recognition of swallowing dysfunction is particularly **poor**.

“Appears” much earlier, esp. when using instrumental assessments



(Patel et al., 2020; Rangwala et al., 2025)

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TABLE 2. Rank of the 24 most bothersome PD related symptoms/conditions in 92 early patients with up to 6 yr of disease duration

Rank	Symptom/condition	Total score	First choice %	Second choice %	Third choice %	3-Choice complaint prevalence (%)
1	Slowness	112	32.6	5.4	13.0	51.1
2	Tremor	101	29.3	8.7	4.3	42.4
3	Stiffness	76	6.5	26.1	10.9	43.5
4	Pain	50	9.8	9.8	5.4	25.0
5	Loss of smell/taste	30	3.3	9.8	3.3	16.3
6	Mood	28	4.3	6.5	4.3	15.2
7	Handwriting	18	2.2	3.3	6.5	12.0
8	Bowel problems	17	2.2	3.3	5.4	10.9
9	Sleep	15	2.2	4.3	1.1	7.6
10	Appetite/weight	13	0.0	3.3	7.6	10.9
11	Restless legs	11	1.1	1.1	6.5	8.7
12	Sexual dysfunction	10	2.2	1.1	2.2	5.4
13	Urinary problems	9	1.1	2.2	2.2	5.4
14	Fluctuating response to medication	8	1.1	2.2	1.1	4.3
15	Drooling	7	1.1	1.1	2.2	4.3
-	Sweating	7	0.0	1.1	5.4	6.5
17	Hallucinations/delusions	6	0.0	1.1	4.3	5.4
-	Memory	6	0.0	2.2	2.2	4.3
19	Compulsive behavior	5	1.1	1.1	0	2.1
20	Falls	4	0.0	1.1	2.2	3.2
-	Freezing	4	0.0	1.1	2.2	3.2
-	Speech	4	0.0	1.1	2.2	3.2
23	Fatigue	3	0.0	1.1	1.1	2.2
-	Swallowing	3	0.0	1.1	1.1	2.2
Other		5	0.0	1.1	3.3	4.3

**Most bothersome symptoms in early PD (0-6yrs)**

**SLOWNESS  
TREMOR  
STIFFNESS  
PAIN**

Politis M et al.. Mov Disord. 2010 Aug 15;25(11):1646-51

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**TABLE 3.** Rank of the 24 most bothersome PD related symptoms/conditions in 173 advanced patients with more than 6 yr of disease duration

Rank	Symptom/condition	Total score	First choice %	Second choice %	Third choice %	3-Choice complaint prevalence (%)
1	Fluctuating response to medication	115	15.0	8.1	5.2	28.3
2	Mood	96	7.5	12.1	8.7	28.3
3	Drooling	85	10.4	6.9	4.0	21.4
4	Sleep	83	9.8	5.2	8.1	23.1
5	Tremor	67	8.1	5.2	4.0	17.3
6	Pain	60	6.4	5.8	4.0	16.2
7	Bowel problems	46	4.0	4.0	6.4	14.5
8	Urinary problems	40	2.9	5.2	4.0	12.1
9	Falls	39	4.0	4.0	2.3	10.4
10	Appetite/weight	36	2.3	4.6	4.6	11.6
11	Slowness	34	3.5	3.5	2.3	9.2
12	Fatigue	31	2.3	2.9	5.2	10.4
13	Sexual dysfunction	29	4.6	1.2	0.6	6.4
14	Hallucinations/delusions	26	2.3	2.9	2.3	7.5
-	Restless legs	26	1.7	2.9	4.0	8.7
-	Speech	26	1.2	3.5	4.6	9.2
17	Compulsive behavior	25	3.5	1.2	1.7	6.4
18	Handwriting	23	2.3	1.7	2.9	6.9
-	Loss of smell/taste	23	1.7	1.7	4.6	8.1
-	Sweating	23	1.2	2.9	4.0	8.1
21	Stiffness	22	1.2	3.5	2.3	6.9
-	Swallowing	22	0.0	4.6	3.5	8.1
23	Freezing	21	2.3	1.7	1.7	5.8
-	Memory	21	1.2	1.7	5.2	8.1
Other		19	0.6	2.9	3.5	6.9

**Most bothersome PD related symptoms (more than 6y)**

**FLUCTUATION IN MEDS  
MOOD  
DROOLING  
SLEEP**

Politis M et al.. Mov Disord. 2010 Aug 15;25(11):1646-51

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Dysphagia  
https://doi.org/10.1007/s00455-021-10301-8

ORIGINAL ARTICLE

**Comparison of Patient-Reported and Caregiver-Reported Swallowing-Related Quality of Life in Parkinson's Disease**

Allie S. Zimmerman<sup>1</sup> · Samantha Shune<sup>2</sup> · Kimberly G. Smith<sup>1</sup> · Julie M. Estis<sup>1</sup> · Kendrea L. Garand<sup>1</sup>

Received: 30 July 2020 / Accepted: 31 March 2021



Choking, drooling, and meal refusal are highly visible

Internal symptoms like nausea and constipation are not as visible

These "internal issues" are the biggest drivers of disagreement

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## Implications are widespread



- Drooling
- Social isolation
- Mealtime pleasure
- Medication efficacy

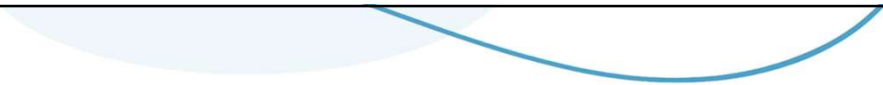
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## And potentially **serious...**



- Reflux
- Weight loss
- Pneumonia

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**WHY?**

Why is it important to assess symptom fluctuations?



**HOW?**

**Define what to notice**  
 Define how to report it to your Dr  
 Define how can families help

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## What to notice

### What is the minimal worth tracking?

2.3 CHEWING AND SWALLOWING		2.2 SALIVA & DROOLING	SCORE
Over the past week, have you usually had problems swallowing pills or eating meals? Do you need your pills cut or crushed or your meals to be made soft, chopped or blended to avoid choking?	<input type="checkbox"/>	Over the past week, have you usually had too much saliva during when you are awake or when you sleep?	<input type="checkbox"/>
0: Normal: No problems. 1: Slight: I am aware of slowness in my chewing or increased effort at swallowing, but I do not choke or need to have my food specially prepared. 2: Mild: I need to have my pills cut or my food specially prepared because of chewing or swallowing problems, but I have not choked over the past week. 3: Moderate: I choked at least once in the past week. 4: Severe: Because of chewing and swallowing problems, I need a feeding tube.		0: Normal: Not at all (no problems). 1: Slight: I have too much saliva, but do not drool. 2: Mild: I have some drooling during sleep, but none when I am awake. 3: Moderate: I have some drooling when I am awake, but I usually do not need tissues or a handkerchief. 4: Severe: I have so much drooling that I regularly need to use tissues or a handkerchief to protect my clothes.	

MDS-UPDRS Specific to Swallowing

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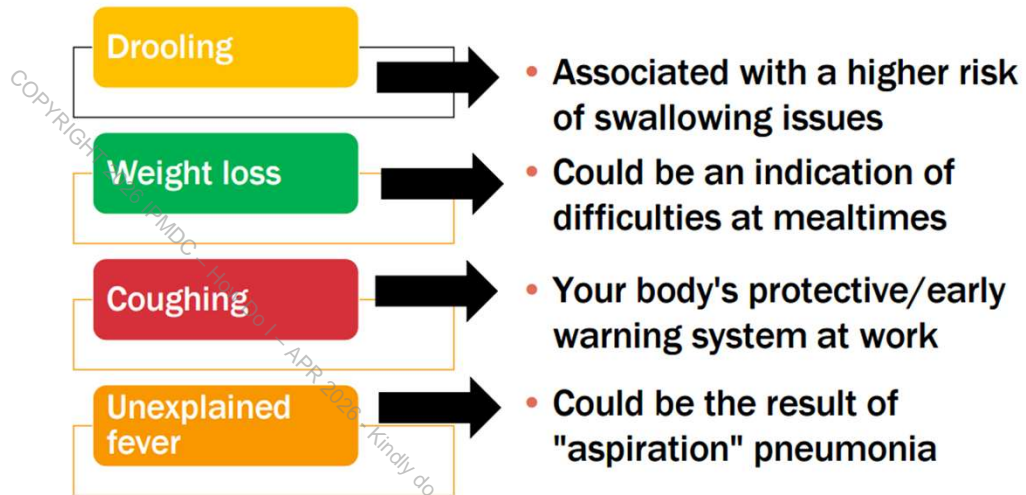
<b>2.3 CHEWING AND SWALLOWING</b>		
Over the past week, have you usually had problems swallowing pills or eating meals? Do you need your pills cut or crushed or your meals to be made soft, chopped or blended to avoid choking?		
0: Normal:	No problems.	
1: Slight:	I am aware of slowness in my chewing or increased effort at swallowing, but I do not choke or need to have my food specially prepared.	
2: Mild:	I need to have my pills cut or my food specially prepared because of chewing or swallowing problems, but I have not choked over the past week.	<input type="checkbox"/>
3: Moderate:	I choked at least once in the past week.	
4: Severe:	Because of chewing and swallowing problems, I need a feeding tube.	
<i>MDS-UPDRS Specific to Swallowing</i>		

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<b>2.2 SALIVA &amp; DROOLING</b>		<b>SCORE</b>
Over the past week, have you usually had too much saliva during when you are awake or when you sleep?		
0: Normal:	Not at all (no problems).	
1: Slight:	I have too much saliva, but do not drool.	
2: Mild:	I have some drooling during sleep, but none when I am awake.	
3: Moderate:	I have some drooling when I am awake, but I usually do not need tissues or a handkerchief.	<input type="checkbox"/>
4: Severe:	I have so much drooling that I regularly need to use tissues or a handkerchief to protect my clothes.	
<i>MDS-UPDRS Specific to Swallowing</i>		

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## Other key indicators of swallowing dysfunction to keep track



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## Learn to recognize factors that make it worse



Fatigue



Feeling **anxious, depressed, or apathetic.**



Distracting environments



**Brain Fog** and other cognitive changes



**Medication** difficulties

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**Learn to recognize factors that make it better**

 SOCIALIZATION

 Optimized foods – easy to eat

 Enhanced eating environment

 Optimized medication

 Find ways to manage **anxiety, depression or fear.**

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**Warning signs that need immediate attention**

When is something urgent?

- Sudden worsening at meals
- Episode of choking
- A complete inability to swallow
- Pneumonia (or other recurrent respiratory infections)

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Optimally, an “objective” instrumented exam

<p>X-Ray Video</p>	<p>Camera</p>

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**WHY?**

Why is it important to assess swallowing in PD?



**HOW?**

Define what to notice  
**Define how to report it to your Dr**  
 Define how can families help

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## Questionnaires can start the conversation

**IMPORTANT NOTE:** We understand that you may have a number of physical problems. Sometimes it is hard to separate these from swallowing difficulties, but we hope that you can do your best to concentrate only on your swallowing problem. Thank you for your efforts in completing this questionnaire.

1. Below are some general statements that people with swallowing problems might mention. In the last month, how true have the following statements been for you?

	(circle one number on each line)				
	Very much true	Quite a bit true	Somewhat true	A little true	Not at all true
Dealing with my swallowing problem is very difficult.	1	2	3	4	5
My swallowing problem is a major distraction in my life.	1	2	3	4	5

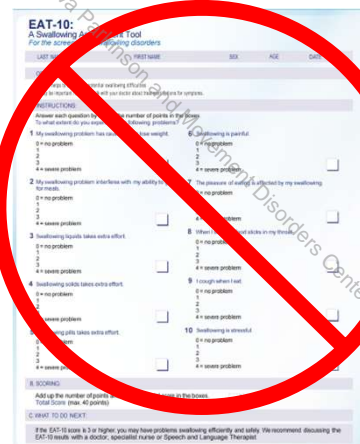
2. Below are aspects of day-to-day eating that people with swallowing problems sometimes talk about. In the last month, how true have the following statements been for you?

	(circle one number on each line)				
	Very much true	Quite a bit true	Somewhat true	A little true	Not at all true
Most days, I don't care if I eat or not.	1	2	3	4	5
It takes me longer to eat than other people.	1	2	3	4	5
I'm rarely hungry anymore.	1	2	3	4	5
It takes me forever to eat a meal.	1	2	3	4	5
I don't enjoy eating anymore.	1	2	3	4	5

**SWAL QOL**

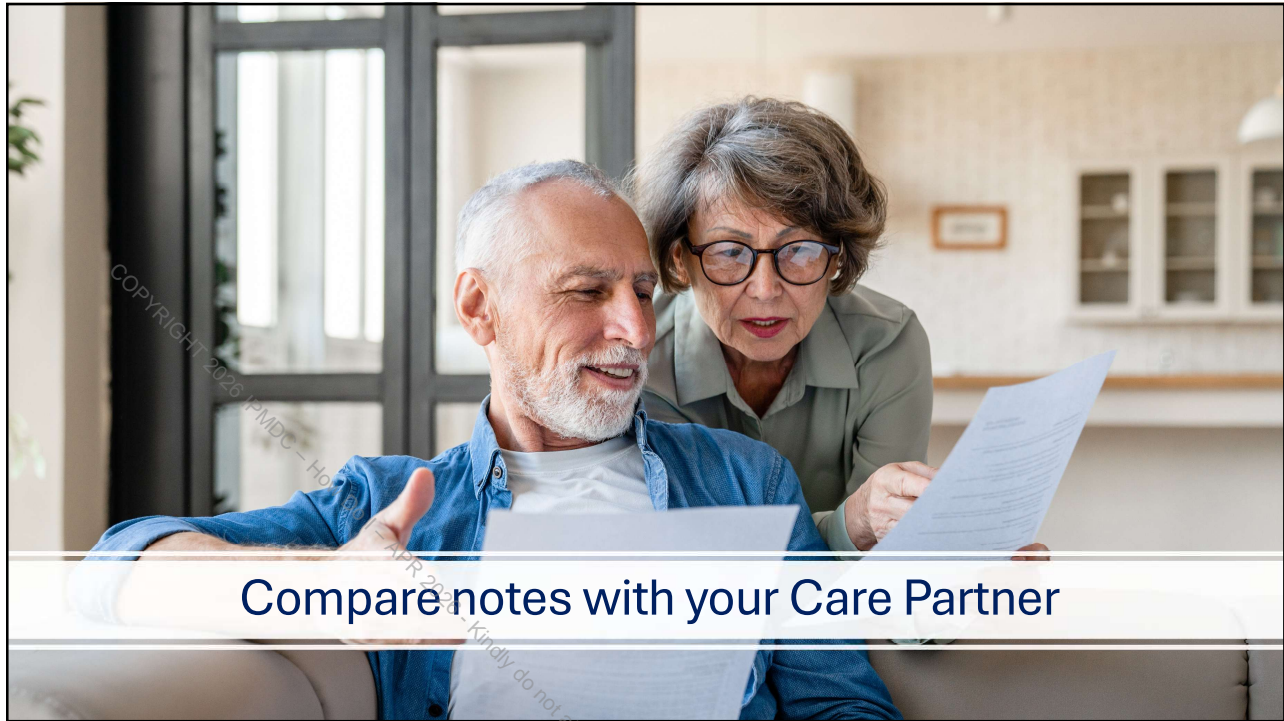
Questions	0 = Never	1 = Seldom (once a month or less)	2 = Frequently (1-7 times a week)	3 = Very Frequently (> 7 times a week)
1. Do you experience difficulty chewing solid food like an apple, chicken, or cracker?	0	1	2	3
2. Are there any food residues in your mouth, cheeks, under your tongue, or stuck to the roof of your mouth after swallowing?	0	1	2	3
3. Does food or liquid come out of your nose when you eat or drink?	0	1	2	3
4. Does chewed up food dribble from your mouth?	0	1	2	3
5. Do you feel you have too much saliva in your mouth (do you drool or have difficulty swallowing your saliva)?	0	1	2	3
6. Do you swallow chewed up food several times before it goes down your throat?	0	1	2	3
7. Do you experience difficulty in swallowing solid food (like apples or crackers get stuck in your throat)?	0	1	2	3
8. Do you experience difficulty in swallowing pureed food?	0	1	2	3
9. While eating, do you feel as if a lump of food is stuck in your throat?	0	1	2	3
10. Do you cough while swallowing liquids?	0	1	2	3
11. Do you cough while swallowing solid food?	0	1	2	3
12. Immediately after eating or drinking, do you experience a change in your voice, such as hoarseness or wetness?	0	1	2	3
13. Other than during meals, do you experience coughing or difficulty breathing as a result of saliva entering your windpipe?	0	1	2	3
14. Do you experience difficulty breathing during meals?	0	1	2	3
15. Have you suffered from a respiratory infection (such as pneumonia, bronchitis) in the past year? (Circle one)	YES	NO		

**SDQ**



**EAT 10**

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Compare notes with your Care Partner

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### Make your own symptom diary

Date of appointment: \_\_\_\_\_

**How to use:** You fill in columns 1–3 yourself. Your care partner fills in the CP column separately. Bring both to your appointment.

Ask yourself:	My problem 1	My problem 2	My problem 3	Care partner's Problem 1	Care partner's Problem 2
<b>Is it new?</b> <i>First time or recurring?</i>					
<b>Getting better, worse, or staying the same?</b> <i>Any unpredictable changes?</i>					
<b>How often &amp; when?</b> <i>Frequency, time of day, duration</i>					
<b>Impact on daily life</b> <i>Activities, social life, independence</i>					
<b>Effect of medication</b> <i>Does it improve after the next dose?</i>					
<b>What makes it worse?</b> <i>Triggers, stress, sleep, activity level</i>					
<b>What makes it better?</b> <i>Rest, meds, movement, timing</i>					
<b>Your view vs carepartners</b> <i>Do you and your care partner see this differently? If yes, how?</i>					
Any lifestyle or habits changed? _____					

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**MyChart**

**Report to your doctor more effectively**

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**Dear Dr...**

Novelty

I have noticed a **recent** problem with my swallowing, which has **worsened** over the **last month**.

Severity

I find myself spending a **lot more time at meals**, which affects my ability to **socialize**. To **get enough calories** at a meal, I need to really focus on eating. While I can usually get through a meal without issue, my spouse is concerned about choking events.

Impact

Carepartner

This happens **most days**, most noticeably at **dinner time**. It's a little easier if I've taken my **medication**.

Factors that make it worse & better

Medication relation

Frequency

Time of day

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**WHY?** | Why is it important to assess swallowing in PD?

**HOW?** | Define what to notice  
 Define how to report it to your Dr  
**Define how can families help**

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## How care partners can help - REPORTING

Notice changes the PWP may miss

Recognize patterns and identify trends

Help in recording and reporting symptoms

Support planning around "better moments"

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## Heimlich maneuver

1. Shock due to suffocation
2. Stand behind the person
3. Make a fist with one hand
4. Impact area
5. Example of hand position
6. Press firmly on the victim's abdomen
7. Bend your elbows sharply
8. Perform the maneuver 5 times until the object is cleared from the airway.

Familiarize yourself with safety measures

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## Including personal safety measures

1. Try to cough out the foreign object
2. Make a fist and place it just above belly button
3. You can also lean over a table edge or chair to add force

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## Consider an anti-choking device



<https://lifevac.net/>

- LifeVac is currently the only FDA-approved device
- Recommended as second-line intervention (after Heimlich, etc.)
- Be sure to trial it for you, “need” it, and keep it where it’s readily accessible

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## Take-home messages



Swallowing issues are common and may occur earlier.



Learning how to give useful information about your **swallowing** is key to better manage it.



**Families** can help by notice changes you might not see, and help record patterns.

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## Thank you for Coming

We hope the information was useful.

Josefa Domingos & John Dean

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## EMST 150

- Strong evidence for improving swallowing in individuals with PD
  - + drooling
  - + aspects of communication

<https://emst150.com>

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### Swallowing Disturbances Questionnaire (SDQ)

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Question	0 Never	1 Seldom (once a month or less)	2 Frequently (1-7 times a week)	3 Very frequently (>7 times a week)
1 Do you experience difficulty chewing solid food, like an apple, cookie or a cracker?				
2 Are there any food residues in your mouth, cheeks, under your tongue or stuck to your palate after swallowing?				
3 Does food or liquid come out of your nose when you eat or drink?				
4 Does chewed-up food dribble from your mouth?				
5 Do you feel you have too much saliva in your mouth; do you drool or have difficulty swallowing your saliva?				
6 Do you need to swallow chewed-up food several times before it goes down your throat?				
7 Do you experience difficulty in swallowing solid food (i.e., do apples or crackers get stuck in your throat)?				
8 Do you experience difficulty in swallowing pureed food?				
9 While eating, do you feel as if a lump of food is stuck in your throat?				
10 Do you cough while swallowing liquids?				
11 Do you cough while swallowing solid foods?				
12 Do you experience a change in your voice, such as hoarseness or reduced intensity immediately after eating or drinking?				
13 Other than during meals, do you experience coughing or difficulty breathing as a result of saliva entering your windpipe?				
14 Do you experience difficulty in breathing during meals?				
15 Have you suffered from a respiratory infection (pneumonia, bronchitis) during the past year?	Yes		No	

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