

Advanced Directives Guide for PSC Patients and Families

Purpose

This document provides a structured framework for primary sclerosing cholangitis (PSC) patients and their families to record healthcare preferences, designate decision-makers, and communicate values regarding future medical care. It ensures that care aligns with the patient's wishes, especially during advanced stages of illness or when the patient cannot make decisions independently.

Patient Information

Field	Details
Full Name	
Date of Birth	
Medical Record Number	
Primary Physician	
Specialist (Hepatologist/Gastroenterologist)	
Emergency Contact	

Understanding PSC and Future Care Planning

Primary Sclerosing Cholangitis is a chronic liver disease that can progress over time, potentially leading to complications such as cirrhosis, portal hypertension, or the need for liver transplantation. Advanced directives help ensure that medical decisions reflect the patient's values and preferences throughout the disease course.

Section 1: Healthcare Proxy (Medical Power of Attorney)

Designate a trusted individual to make healthcare decisions if the patient becomes unable to do so.

Field	Details
Healthcare Proxy Name	
Relationship to Patient	
Phone Number	
Alternate Proxy Name	
Relationship to Patient	
Phone Number	

Responsibilities of Proxy:

- Communicate patient's wishes to healthcare providers
- Make decisions consistent with patient's values and goals
- Review and update directives as the patient's condition changes

Section 2: Treatment Preferences

A. Hospitalization and Intensive Care

Question	Preference (Yes/No/Unsure)	Notes
Hospitalization for severe PSC complications		
Admission to Intensive Care Unit (ICU)		
Use of mechanical ventilation (breathing machine)		
Use of dialysis for kidney failure		

B. Liver Transplant Considerations

Question	Preference (Yes/No/Unsure)	Notes
Desire to be evaluated for liver transplantation		
Willingness to undergo transplant surgery if eligible		
Preference for palliative care if not a transplant candidate		

C. Nutrition and Hydration

Question	Preference (Yes/No/Unsure)	Notes
Artificial nutrition (feeding tube)		
Intravenous hydration		

D. Pain and Symptom Management

Preference	Notes
Desire for maximum comfort measures, even if it may shorten life	
Preference for minimal sedation to remain alert	

Section 3: Palliative and Hospice Care

Question	Preference (Yes/No/Unsure)	Notes
Desire to receive palliative care alongside active treatment		
Preference for hospice care when treatment is no longer effective		
Preferred location for end-of-life care (home, hospice facility, hospital)		

Section 4: Organ and Tissue Donation

Question	Preference (Yes/No/Unsure)	Notes
Consent to donate organs or tissues for transplantation		
Consent to donate for research related to PSC		

Section 5: Spiritual and Emotional Preferences

Field	Details
Religious or spiritual affiliation	
Preferred spiritual advisor or clergy contact	
Specific rituals or practices to be observed	
Emotional support preferences for family and caregivers	

Section 6: Communication and Documentation

Action	Completed (Y/N)	Date
Discussed directives with healthcare proxy		
Shared copy with primary physician		
Shared copy with hepatology team		
Shared copy with family members		
Uploaded to electronic medical record		

Section 7: Review and Updates

Advanced directives should be reviewed regularly, especially after major health changes or hospitalizations.

Review Date	Reviewed By	Changes Made	Signature

Section 8: Signatures

Name	Role	Signature	Date
Patient			
Healthcare Proxy			
Witness 1			
Witness 2			
Physician			

Notes for Families

- Keep copies of this document in accessible locations.
- Inform all healthcare providers about the existence of these directives.
- Revisit preferences as the disease progresses or treatment options evolve.

Summary

This advanced directives guide empowers PSC patients and their families to make informed, compassionate decisions that honor the patient's values and medical goals. It serves as a living document to support communication, dignity, and continuity of care throughout the PSC journey.