

Take notes and keep on-going records

Many ACC patients have benefited from keeping a *personal documentation portfolio* of their medical records to support successful decision-making. There are also some *general tips* provided here that others have found helpful.

Personal Documentation Portfolio Content

Things to include in your documentation portfolio	Histology: What is the tumor's growth pattern (solid, cribriform or tubular)?
	Perineural invasion: Has the tumor infiltrated major nerves?
	Surgical summaries (if you have surgery): Was your tumor fully resected (taken out)? Were "clean" margins achieved in the surgery (does the surgeon believe the area around the tumor is free of cancer cells)?
	Dates of key procedures with doctors summaries of what was done or found.
	A copy of your pathology slides used to diagnose the disease.
	Copies of all xray, CT, MRI, PET scans as well as photos from procedures like bronchoscopies, etc.

General Helpful Tips

Other Helpful Tips	Consult with doctors who have experience with ACC
	Get a second (or third) opinion
	Bring a friend or family to appointments
	Prepare a list of questions
	Take notes at appointment so you can recall details later
	Ask for copies of physician notes and lab results after each appointment
	Request copies of X-Ray, CT, MRI and other imaging studies on CD-ROM before you leave your appointments
	Request any available written educational resources on procedures or tests.
	Ask questions to understand what will happen to you before, during and after any procedure or series of treatments
	Make sure you get a clear explanation of all possible side effects prior to treatment(s)
	Ask for clarity of acute/short-term, medium-term and long-term side effects